Transforming Queer Health Technologies Through Community-Based Systems Design

Calvin A. Liang

A dissertation
submitted in partial fulfillment of the
requirements for the degree of

Doctor of Philosophy

University of Washington
2023

Reading Committee:
Sean Munson, Co-Chair
Julie Kientz, Co-Chair
Sucheta Ghoshal
Andrea Hartzler

Program Authorized to Offer Degree:
Human Centered Design and Engineering

University of Washington

Abstract

Transforming Queer Health Technologies Through Community-Based Systems Design

Calvin A. Liang

Chairs of the Supervisory Committee:
Julie A. Kientz
Sean A. Munson
Department of Human Centered Design and Engineering

Technologists are often motivated to do good in the world, laying out grand visions for how to optimize systems, automate tedious tasks, and expand what is possible. However, these innovations can create or exacerbate inequities, foregoing the needs of marginalized people in favor of novelty for those who already enjoy certain advantages. This tradeoff between innovation and fairness, however, is a false dichotomy. Through this dissertation, I argue how technology designers can carefully consider the impacts on marginalized people and the harms that can occur when systems are poorly designed, built, and evaluated and that, in turn, this attention can actually drive innovation. To this end, this dissertation compiles together queerness, health, and computing to develop a framework for designing health systems that counters structural oppression. As I witness, a queer praxis expands the domains of health and computing by confronting their respective and overlapping histories of mistreatment of marginalized people, opening up new paths for co-development in research.

My investigation to accomplish this consists of two parts. First and more broadly, I outline an approach to working with marginalized people in Human-Computer Interaction (HCI) research by identifying four inherent tensions that researchers must attend to—exploitation, membership, disclosure, and allyship. By discussing what makes each tension difficult as well as actions that researchers can take to mitigate harms, I underscore the value of working with marginalization in the face of complexity. I then apply these lessons of conducting HCI research with marginalized people into a specific case study of co-designing a health technology for and with trans and queer youth, known as Project Online Interactive Sex Education Tool (OISET). Here, I report on two studies that uncover crucial needs of this tool: first, high-level design needs related to inclusion and safety, and second, privacy and security concerns and requisite design-based mitigation strategies.

By connecting these two sections across multiple chapters, I exemplify how HCI researchers can integrate intersectionally holistic conceptualizations, community-based participatory values, and systems-level thinking into their own approaches and research contexts. Grounded in this analysis, I build up to six commitments for HCI researchers invested in designing sociotechnical systems for health equity. With these commitments in mind, I illuminate a path forward and demonstrate that an equitable and liberatory future of technology development is not only possible but within our reach.

TABLE OF CONTENTS

Acknowledgments

I am lucky, grateful, and overjoyed for the love, support, and care that has surrounded me throughout my doctoral career. The following people have not only changed the work presented in this dissertation but have also helped shape me into the person I am today.

Thank you to my committee members, Dr. Julie Kientz, Dr. Sean Munson, Dr. Sucheta Ghoshal, Dr. Alic Shook, and Dr. Andrea Hartzler. Julie and Sean, you took a chance on me when you accepted me into our department, and I sincerely mean that this opportunity to work with you both has been a dream come true. Thank you for helping me achieve my dreams, for your constant support through drastic changes to my research agenda and my emotional rollercoasters. The vulnerability that comes through in my research is in large part due to the spaces you have established for me to think in. Thank you for making me feel safe enough to try new things, take stronger stances, and learn to trust my instincts. Thank you for catching all my spelling mistakes, reading too many drafts, and responding to my chaotic slack messages. You have changed my life for the better, and I will always appreciate you.

To Sucheta, Alic, and Andrea, you have all inspired me to be a better researcher, researcher, and activist. Sucheta, you have challenged me to extend how I think about the world, queerness, race, and justice. I will always cherish the time we spent discussing readings together. Alic, you have shown me what it means to put my heart into my work. I am inspired by your strength, your kindness, and your commitments to building a better world. I also must thank Wanda Pratt for suggesting I attend your dissertation defense, which is how we got here in the first place. Andrea, I am inspired by your dedication as a parent. I hope that more parents can be like you. Thank you for always making me feel supported and heard, and I am grateful that we crossed paths.

Thank you to my family, my mom, dad, sister, brother-in-law, and niece. My parents immigrated to the United States in hopes of building a better life for my sister and I, and the love I have for my life right now is thanks to their hard work and sacrifices. My parents have prioritized my education, spent time and energy to teach me, and driven me all around California to go to water polo and swim practices. I have always wanted to make my parents proud. To my sister, Elena, you have always been my role model. I love you all.

This work would not have been possible without numerous collaborators. Thank you to Arpita, Jevan Huston, Os Keyes, Katie Albertson, Florence Williams, David Inwards Breland, Alexis Coatney, Kym Ahrens, and Molly Altman. I also want to thank everyone who has participated in my research, especially the Queer Trans Advisory Board. It is such an honor and so much fun to get to learn together. This work would not have been possible without funding from the Department of Human Centered Design & Engineering, the Center for Diversity and Health Equity at Seattle Children’s Hospital #24090057, and Jacob's Foundation CERES Network.

I have received mentorship from some incredible scholars and people, and I am so inspired by how they think. Thank you to my mentors Kiley Sobel, Andrew Berry, Wendy Roldan, Crystal Lee, Jed Brubaker, Jean Hardy, Alexandra To, Sarah Coppola, David Ribes, Jennifer Turns, and Mary Gray.

Thank you to my graduate school community for giving me space to vent, reading drafts, and making my PhD journey fun. Thank you to my HCDE folks: Neilly Herrera Tan, Akeiylah DeWitt, Jay Cunningham, Sam Kolovson, John Fowler, Hannah Twigg-Smith, Steven Goodman, Kenya Meijia, Melinda McClure Haughey, and Burren Peil. Thank you to my national and international graduate student community: Emily Tseng, Sachin Pendse, Morgan Klaus Scheuerman, Kimberly Allison, Veronica Sheanoda, Jonathan Zong, Dan Delmonaco, Chris Persaud, Benjamin Ale-Ebrahim.

Thank you to my friends across the world who I miss everyday, Dom Granato, Hans Tercek, Jon Adams, Hazen Breen, Jordin Metz, Tatiana Tuccio, Lali Mares, Christine Hasrouni, Alex Sanhueza, Lina Shin, Chelsea Newman, Moira Lavelle, Kaitlyn Johnson, Harry Wood, Sophia Lin, Molly Levene, Russ Weeks, Jack Benoit, Scott Simpson, Cam Mahko, Sarah Mahko, Sam Ladow, Collin Meade, and Deb Frank. A special shout out to my beloved Seattle family, lifting partners, and dumpling group, Zoë Bartholomew, Sheri Soo, Caroline Russell-Troutman, Cliff Mountjoy-Venning, Jeremy Bonnell, Anna Lee, Caroline Ferguson, Christian Selby, Nora White, David Fleming, Kimberly Dacorogna, and Tal August.

I have and always will be grateful for everyone’s love, which has been influential in how I have learned to love myself throughout this process.

Chapter 1. Introduction

Health technologies provide an extensive range of services, tools, and resources for people who can vary in their somatic, cultural, and sociotechnical needs. Ranging from pacemakers to meditation mobile apps to artificial intelligence-based cancer screenings, these systems have vastly improved our ability to diagnose, treat, and care for people's health (Oudshoorn, 2020; Savage, 2020). However, not all experiences with health are created equal. Health inequities have been defined as "the systematic, avoidable and unfair differences in health outcomes'' that exist between people of different social groups and social positions, and pursuing health equity means working to eliminate such disparities (Braveman, 2006; McCartney et al., 2019).

Technology design provides one pathway towards health equity, however researchers have pointed out that sometimes these systems can do more harm than good if they are developed recklessly (Benjamin, 2020; Veinot et al., 2018). In human-computer interaction (HCI) research, scholars have pursued health equity through system design in various ways. Much work has focused upon the equitable and enjoyable delivery of care for marginalized people (e.g., Khan et al., 2023). For instance, Sabin et al. are developing a patient-provider tool that detects any hidden provider biases and gives feedback on how to improve clinical interactions to improve the healthcare experiences of Black, Indigenous People of Color and LGBTQ+ folks (Sabin et et al., 2021). Further work has focused on community engagement for health activism. For instance, Parker et al. have created tools for promoting healthy eating behaviors through community relationality and empowering Black community members to be advocates for change in their neighborhoods (Parker et al., 2012; Grimes et al., 2008). Dillahunt and colleagues have additionally envisioned online tools to support disadvantaged job seekers (Dillahunt et al., 2016; Dillahunt et al., 2019). These examples demonstrate the diverse ways that HCI researchers have operationalized health equity, ranging from patient experiences to community health, and the last example highlights the fact that employment, particularly in the United States, is crucial in order to maintain one's health. With this in mind, it is necessary when working towards health equity to consider factors outside of clinical settings and consider the widespread conditions that influence people's experiences with their health.

Existing frameworks, such as the social determinants of health, reveal how inequities in health experiences stem from conditions in a person's context including their social and community context, economic stability, access to and quality of education, access to and quality of healthcare, and their neighborhood and built environment (Healthy People, 2030). In addition, these models demonstrate how evaluating and providing the best healthcare requires an expansion of how interventionists think of the patient, towards a comprehensive understanding of both who they are as people and how they experience the world around them. Acknowledging and accounting for social identities such as race, class, gender, sexuality, place, ability, and more is one key component to this process, and doing so can help providers and researchers recognize unique health needs.

Despite these revelations and health technology's potential for impactful outcomes, research in health and technology have long histories of exploiting and mistreating marginalized people. Numerous examples uncover a dark lineage of research on marginalized people. In the Syphilis Study at Tuskegee, for example, the Centers for Disease Control and Prevention and the United States Public Health Service deceptively administered syphilis to and knowingly withheld treatment from Black men of low socioeconomic status to understand how the disease affects the body when left untreated (U.S. Centers for Disease Control and Prevention, 2019; Brandt, 1978). This experiment occurred for forty years and is widely considered to be one of the most shameful examples of research misconduct (Katz et al., 2008). As a further example in computing research, scholars have raised numerous ethical flags in the development of automated facial recognition systems specifically used for gender- and sexuality-based detection, raising concerns about outing trans and queer people and threats to their safety and well-being (Wang & Kosinski, 2018; Keyes, 2018). Further, these harmful research practices for research involving marginalized people are still ever-present. A recent study misgendered trans women as "men who have sex with men", thus overlooking a crucial detail that PrEP was less effective for women in the trial who were using estrogen (Deutsch et al., 2015). As this example demonstrates, researchers who fail to fully understand the complexity of people's needs and conditions—in this case, how trans women differ from men who have sex with men—can go on to make inaccurate and dangerous claims.

In response, scholars have specifically called for greater involvement of trans communities in research about trans people (Scheim et al., 2019; Minalga et al., 2022). As Minalga and their co-authors write, "*transgender people urgently need research that results in meaningful progress for our communities. We declare that research on transgender people must benefit transgender people*" (Minalga et al., 2022). To this end, design-based methods offer a counter-strategy to research on, for, and about those who face disparities in their health experiences due to social positions, including trans and queer people. In particular, community-based participatory research (CBPR) and participatory design (PD) transform research paradigms towards working *with* those who are directly affected by these health interventions (Israel et al., 2001; Weinstein et al., 2023). Community-based efforts have led to the creation of resources that serve to advance the state of trans health research. Specifically, Appenroth, Davids, Feuer, Kgositau, and Mugo developed a data manifesto for HIV prevention research with trans and gender-diverse (TGD) people (Appenroth et al., 2021). In doing so, they point out that "the historic failure to conduct meaningful HIV prevention research with TGD populations is yet another act of systemic and institutionalized violence against TGD people. It exacerbates the very health disparities that the HIV field has committed to addressing.” In HCI, researchers have taken up calls to integrate community-collaborative approaches into their own practices (Cooper et al., 2022; Harrington et al., 2019). Similar to health research, partnering with communities who are marginalized and commonly left out of research has robust benefits to technology design, particularly by building systems that avoid reinforcing stigma, bias, and systemic oppression.

United by the advantages of integrating these community-based approaches, this dissertation brings together these two domains to explore how to work towards strengthening equity through the co-development of health technologies. While there are opportunities to extrapolate the lessons developed through this work more widely, I specifically explore trans and queer health and how designers can develop health technologies for trans and queer health justice through community-based systems design.

1.1 Trans and Queer Health Equity

There has been a recent push to investigate the health experiences and needs specific to LGBTQIA+ people (Dean et al., 2000; Healthy People, 2010; Mayer et al., 2008). Due to stigma, discrimination, violence, and other community and structural factors, transgender (trans) and queer people experience critical sexual health disparities (Crosby et al., 2018; Reisnet et al., 2016; McCann et al., 2018; Clark et al., 2017; Reisner et al., 2015; Baral et al., 2013; Garofalo et al., 2006; Turner et al., 2017; Wilson et al., 2010; Veale et al., 2016; Kussin-Shoptaw et al., 2017). Trans and queer youth across the gender spectrum report high rates of sexual risk factors including inconsistent or non-condom use with vaginal and anal sex, and sex under the influence of drugs or alcohol. As a consequence trans and queer people can experience disproportionately high rates of sexually transmitted infections (STIs) compared to cisgender people (Crosby et al., 2018; Clark et al., 2017; Reisner et al., 2015; Baral et al., 2013; Garofalo et al., 2006; Turner et al., 2017; Wilson et al., 2010). These risks are highly affected by social and environmental factors. Trans and queer youth also experience nine forms of violence more often than cisgender peers including intimate partner violence and unwanted sexual contact (Dank et al., 2014; Whitton et al., 2016; Grant et al., 2011; Griner et al., 2020; Reuter et al., 2017; Sterzing et al., 2017). Violence exposures contribute to STI and other sexual risks and to critical mental health outcomes such as depression, anxiety, post-traumatic stress, and suicidality (Reisner et al., 2017; Chakrapani et al., 2017; Smith et al., 2017; Kussin-Shoptaw et al., 2017). Compounding these factors, trans and queer youth also experience gaps in care that can create long-lasting negative effects from adolescent sexual health and relational outcomes. Trans and queer people are less likely to be tested or receive standard-of-care treatments for STIs compared with peers due to transphobia/discrimination, stigma, and mistrust of healthcare systems (Grant et al., 2011; Sharma et al., 2019; Gridley et al., 2016; Dowshen et al., 2017; Fisher et al., 2017; Scheim et al., 2017). This increases the risk of serious health repercussions (e.g., life-threatening infections, infertility, adult mental health sequelae) and increases the likelihood of acquisition of other STIs (Reisner et al., 2016; Smith et al., 2017; Kussin-Shoptaw et al., 2017; Chakrapani et al., 2017; Reuter et al., 2017; Whitton et al., 2016).[1]

In the face of such health inequities, sex education is one form of preventative healthcare that provides an array of short-term and long-term benefits. A review of three decades of research involving the efficacy of comprehensive sex-education identified several positive outcomes, including an “appreciation of sexual diversity, dating and intimate partner violence prevention,

---

[1] This paragraph was written as a collaborative effort with researchers from Seattle Children’s Research Institute, UW Nursing, and SU Nursing.

development of healthy relationships, prevention of child sex abuse, improved social/emotional learning, and increased media literacy" (Goldfarb & Lieberman, 2021). However, these potential benefits of sex education can be entirely undermined by the quality of and barriers to access for a comprehensive sex education. Many students across the United States lack access to evidence-based sex education and instead receive a curriculum centered around abstinence, which has been proven insufficient at reducing the negative health outcomes it purports to address (Bleakley et al., 2006; Stanger-Hall & Hall, 2011). Furthermore, current educational and clinical structures largely ignore trans and queer youths' experiences (Elia & Eliason, 2010). Trans and queer people have different needs than their cis-gender peers and have previously characterized school-based sex education as inadequate and, at times, harmful (Haley et al., 2019). As a consequence of this lack of information, they are at higher risk of several negative health outcomes such as sexually transmitted infections (STIs) and experiencing violence in romantic and sexual relationships (Brennan et al., 2012; Griner et al., 2017; Reuter et al., 2017). Trans and queer youth deserve effective, assets-based, gender affirming sex education; however, how to tailor and deliver this content through a human-centered approach is still an open question.

1.2 Assembling health, queerness, and technology together

The usage and impacts of technology are interconnected with this holistic construction of queer people's health experiences. Given its prevalence in the contexts of both health and everyday life, technology provides an effective mechanism for reaching more queer people, providing personalized care, and addressing health inequities (Haimson et al., 2020; Beare & Stone, 2021). Similar to care provisions, technology can be tailored to meet LGBTQIA+ people's needs. For example, Starks et al. explored how wearables can increase safety for trans people in the physical world (Starks et al., 2019) and Haimson and colleagues identified how pre-2018 Tumblr supported trans users by providing community and allowing for identity exploration (Haimson et al., 2021). As these scholars have demonstrated, technologies that are built with queer communities in mind are powerful tools for providing support and meaning.

Looking across the body of LGBTQIA+-centered research in CSCW and HCI, scholars have focused on the social consequences of being queer online; however, there are opportunities to examine technology's impacts beyond the individual level and toward more communal and structural contributions around health. Maestre et al. model this well by expanding the traditional approach to designing technology for HIV that focuses on treatment management and medical adherence to also account for the broader social landscape, public HIV-related stigma, in design (Maestre et al., 2021). Emerging critical perspectives guide technologists in considering health issues on several levels organized by "downstream" to "upstream" effects: micro (e.g., psychosocial, behavioral, and biological factors), meso (e.g., living and working conditions and social and community networks), and macro (e.g., socioeconomic and political contexts and social hierarchies) (Veinot et al., 2019). Embracing social, economic, and cultural factors when building technology for queer people's health is a step in the right direction, especially considering how technology can also be weaponized against queer people. For instance, many LGBTQ+ people have reported instances of police luring Grindr users into in-person meetups, only to arrest them upon arrival. Furthermore, Veinot et al.'s depiction of the downstream to upstream health disparity ecosystem emphasizes the need for multiple approaches for intervention. Maestre et al.'s findings support the need to supplement HIV medication adherence with social services for people living with HIV so that they are better prepared to handle stigma and social forces impressed upon them. As a result, this dissertation positions "systems design" as an expansive approach that draws from not just information or technological design but also design of policies, services, and organizations.

When thinking about providing healthcare to LGBTQ+ patients and addressing these existing inequities, Mayer and colleagues recommend an examination of the histories of stigmatization, cultural influences on healthcare experiences, and existing barriers that queer people face (Mayer et al., 2008). Researchers can begin to establish queer-specific insights into these areas by engaging in relational work with LGBTQIA+ communities, through participatory and/or community-based methods (e.g., Delmonaco et al., 2020). These approaches can be especially generative when working with youth by accounting for power imbalances through direct engagement with a population that adults can too often speak on behalf of. One notable example of this comes from Ghosh and colleagues, where youth shared how they felt about their parents monitoring their online activity, revealing poor experiences with both the surveillance tech and their parental relationships (Ghosh et al., 2018). Insights like these that are derived directly from youth themselves can guide designers to create better experiences for child users.

Recent work, however, has shown how researchers are capable of disrupting the equitable goals inherent to both community-based participatory research (CBPR) and participatory design (PD) by prioritizing their own needs over those of the participants, failing to account for power differentials, and more (Harrington et al., 2019; Green, 2021). This leaves room for more discussion on how to mindfully balance researchers' interests and positionalities in these community engagements without perpetuating harms toward research participants.

1.3 Research Questions

Following a holistic approach, there are many opportunities to explore how queerness, health, and technology come together. On their own, each area is rich with specific dilemmas and demands, and combining them together can yield new, complex, and entangled lessons for how researchers build systems for health equity. This dissertation is situated among emerging work to accomplish just that as I delve into Project Online Interactive Sex Education Tool (OISET), a series of studies centered around designing sex education resources for/with transgender and queer youth. Through engagements with this work, I explore the following questions in this dissertation:

> **RQ1**: How can the design of an online interactive sex education tool support (or not support) trans and queer youth with their health needs?
>
> **RQ2**: What might we learn about designing sociotechnical systems for health equity from designing a sex education tool for/with trans and queer youth?

To address RQ1, I report lessons from applying a human-centered design process to an OISET for and with transgender and queer youth that outline the system's design needs, privacy and security needs, and overlaps between the two. To address RQ2, I connect four tensions inherent to HCI research with marginalized people that I previously developed to Project OISET.

1.4 Dissertation Contributions

My dissertation makes the following claims:

> Designing technological interventions that promote trans and queer health equity requires: 1) an understanding of how queer people's holistic needs converge and diverge among a range of experiences with marginalization and power, 2) intentional reflections regarding researcher's own positionality and impact, and 3) recognition that

technological artifacts alone are insufficient at advancing structural change without additional social support, systems thinking, and community engagement.

Through a study of HCI scholars' approaches to research with marginalized people and a multi-year project to design an online sex education resource for trans youth, I reflect on approaches for designing health equity technologies that embrace reflexivity, counteract exploitation, and build towards a more equitable future. This dissertation also contributes specific considerations for the design of health equity technologies for trans and queer people, which include designing safe and inclusive online experiences and proactively embedding privacy and security protections. These considerations make up a holistic approach to health equity systems design that engages participation of people directly impacted by these design decisions, positions design as a component rather than a panacea for liberation, and looks across multiple levels of power, domination, and resistance.

The following table summarizes each study's research questions, methods, and contributions, and how they relate to the dissertation's greater claims. In particular, Chapter 3 provides a theoretical framework and ethically-oriented methods for the following chapters. Chapter 4 identifies a range of design needs that trans and queer youth have for the development of a sex education online tool, and Chapter 5 draws from participatory threat modeling to expand an existing privacy-by-design framework for this context.

Study	**Chapter 3: Embracing Four Tensions in HCI Research with Marginalized People**	**Chapter 4: Designing an Online Sex Education Tool for Transgender and Queer Youth**	**Chapter 5: Understanding the Privacy and Security Needs of an OISET for Transgender and Queer Youth**

RQs	*3a.* How do HCI researchers engage in and reflect on research with marginalized people? *3b.* How do HCI researchers see their research affecting participants, and how do they reflect on and adjust their practices as a result? *3c.* How do HCI researchers engage in and reflect on research with marginalized people as it affects researchers? 3d. How do the norms of the field of HCI affect marginalized people as researchers and, further, those researchers' interactions with participants?	*4a.* How can the design of an online interactive sex education tool support (or not support) trans and queer youth with their health needs? *4b.* How do trans and queer[2] youth prefer to receive sex education-related information? *4c.* What role can design and technology play in developing effective sex education resources for trans and queer youth? *4d.* How can we adapt current participatory design methods to gain insight into difficult-to-discuss topics like sexual health?	*5a.* What are existing threats that trans and queer youth face today? What constraints exist that limit our abilities to intervene? What are current mitigation strategies that people use to address these threats and constraints? *5b.* What current design patterns for trans/queer technologies exist that protect privacy and security?
Methods	Qualitative surveys, interviews, or both with 24 HCI researchers, located primarily in the United States	Qualitative series of participatory focus groups, asynchronous remote communities (ARC), and co-design with trans and queer youth	Qualitative focus groups and interviews with people who work at or volunteer at organizations that provide services to trans and queer youth Co-Design sessions with community advisory board made up of trans and queer youth ages 15-25
Contributions	*C3.1* Empirically, I show how current HCI researchers navigate ethical considerations when doing research with marginalized people.	*C4.1* Empirically, identification of preferences for how trans and queer youth would like to receive different sexual health-related	*C5.1* Establishes holistic privacy and security needs of an online interactive sex education tool by identifying existing threats, constraints, and mitigation strategies for

---

[2] We have since updated our language to *trans and queer* to reflect the non-normative and open nature of these identities, rather than solely highlighting the range of gender identities.

	C3.2 Theoretical contributions involving four tensions inherent to HCI research with marginalized people: exploitation, membership, disclosure, and allyship.	information and design needs for an online sex education resource for trans and queer youth, and *C4.2* Novel methodological approaches that can be used to explore sensitive topics with teens, including combining in-person focus groups with an online ARC study, flexibility, transparency, and co-design principles *C4.3* Wireframes for an OISET to support trans and queer youth's sexual health needs	protecting trans and queer youth's privacy and security *C5.2* Connects HCI methods with privacy-by-design framework by extending participatory threat-modeling with trans and queer youth and their network and thereby detailing elements of a queer approach to privacy-by-design *C5.3* Reviews current design patterns for protecting trans and queer youth privacy and security and provides wireframes for an OISET's privacy and security settings *C5.4* Methodologically extends participatory threat-modeling with a trans and queer youth community advisory board and their support network towards a holistic understanding of needs
Relation to Dissertation	Establishes ethical considerations and theoretical framing around four tensions for methods, analysis, and study decisions in future studies	Initializes an exploration into the holistic sexual health needs of trans and queer youth by identifying both design requirements and additional considerations	Demonstrates how to engage marginalized people in the development of future technologies through participatory threat-modeling with trans and queer youth

Table 1. Three studies contributing to my dissertation.

1.5 Author Positionality

My epistemological stance towards research has evolved over time. I have sought to move away from my positivist training and now follow an interpretivist form of inquiry that builds knowledge, rather than one that sets out to prove it (Orlikowski & Baroudi, 1991). I value the co-construction of knowledge with participants and emphasize the importance of sharing lived experiences as a conduit of knowledge. This is shown through our research questions that are meant to explain a current variety of approaches to work with marginalized people in HCI (summative) and inform the future of such research (formative) (Palen, 2014). I also have first-hand experience with discrimination and harm based on my identities and my experiences with technology. I also am made up of various, interweaving identities, some marginalized and others that have granted me privileges that I cannot ignore. It is through this unique combination of identities and understanding as both the oppressed and the oppressor that they have pursued and carried out this work.

1.6 Dissertation Overview

My dissertation is organized in 6 chapters.

In Chapter 2, Related Work, I describe the theories, methods, and related literature that guide this dissertation. I first situate my dissertation among existing bodies of work involving sex education needs for trans people, LGBTQ youth online, and designing with youth through participatory methods. Following this, I outline how Queer Theory, Design Justice, and Intersectionality inform the methods and ethos of this dissertation.

In Chapter 3, I present a study focused on considerations for researchers who engage in HCI research with marginalized people. In this study, we explored how HCI researchers reflected on their work with marginalized people on three interactional axes: researcher to researcher, researcher to participant, and HCI as a field to researchers to participants. Constructed through qualitative engagements with 24 HCI researchers, I introduce four tensions inherent to this form of research—exploitation, membership, disclosure, and allyship. I discuss ways to navigate and embrace the paradoxical nature of each towards a more justice-oriented future of HCI research.

This chapter establishes ethical considerations and theoretical framing around four tensions for methods, analysis, and study decisions for the next two chapters.

Chapters 4 and 5 outline two studies from Project OISET, or Online Interactive Sex Education Tool. In Chapter 4, Designing an Online Sex Education Tool for Transgender and Queer Youth, I first describe an initial participatory design needs-assessment of an OISET with 19 youth in the greater Seattle area. I report on the design-related findings specific to an OISET for trans and queer youth specifically around designing for safety and designing for inclusion. This study initializes an exploration into the holistic sexual health needs of trans and queer youth by identifying both design requirements and additional considerations for future systems design.

Next in Chapter 5, Understanding the Privacy and Security Needs of an OISET for Trans and Queer Youth, I detail findings pertaining to a study focused on the privacy and security needs of the OISET through participatory threat-modeling. By engaging with people who serve trans and queer youth in a variety of ways, I identify existing threats, constraints, and mitigation strategies for protecting trans and queer youths' data and subsequent safety. I further validate these findings with a community advisory board made up of trans and queer youth from across the United States. With this community advisory board, we co-designed wireframes to envision how an OISET can address the needs presented throughout this study. Here, I demonstrate how to engage marginalized people in the development of future technologies through participatory threat-modeling with trans and queer youth.

In Chapter 6, Discussion, I connect the four tensions outlined in Chapter 3 to Project OISET. Through this reflection, I demonstrate how I have taken these tensions into consideration and integrated them into my research practices. In addition, I identify several commitments for researchers and practitioners looking to engage in health equity research through community-based participatory research (CBPR), including commitments to intersectional inclusion, privacy and security, systems thinking for health equity, reflexivity and positionality, impact, and queerness.

Chapter 2. Related Work

In this chapter, I summarize related work in three areas as well as theoretical foundations that inspire my research. I first outline previous findings related to sex education needs for trans youth. Next, I discuss scholarship on the online experiences of LGBTQ youth. Third, I review participatory methods when designing with youth including participatory design and community-based participatory research. I then summarize theories that I draw upon to understand social power dynamics: queer theory, systems of oppression, and intersectionality.

2.1 Sex Education Needs for Transgender Youth

Trans youth—people ages 12 to 21 years old who do not feel like their sex assigned at birth accurately captures who they are—have unique sexual health needs (Olson-Kennedy et al., 2016). As others have noted, sexual health for trans youth is more than just sexual behavior; it encompasses internal and social dynamics such as challenges with body image, sexual anatomy, gender dysphoria, disclosing gender to a partner, and communicating with a sexual and/or romantic partner (Olson-Kennedy et al., 2016).

Despite the clear need for tailored, gender-affirming sex education resources for trans youth, only a few studies have explored the specific sexual health requirements of this group. In a 2019 study, Haley et al. revealed two key insights in regard to what sexual health information genderdiverse youth look for and where they get such knowledge (Haley et al., 2019). First, they report that trans and non-binary youth commonly receive sexual health information from their schools, healthcare providers, peers, romantic partners, and online sources, but the first two sources are limited due to irrelevant curriculum and varying quality of interactions with providers (including experiences that can be ignorant or even harmful). Second, they surfaced eight sexual health content needs described by trans youth: puberty-related gender dysphoria, non-medical gender-affirming interventions, medical gender-affirming interventions, consent and relationships, sex and desire, sexually transmitted infection prevention, fertility and contraception, and healthcare access. Delmonaco and colleagues built upon these findings to identify three health care topics that LGBTQ+ youth wanted in an online website, resources for mental health, sexual health, and navigating services (e.g., health insurance, finding inclusive providers) (Delmonaco et al., 2022).

Researchers have also identified several tensions in providing sexual and reproductive health content for trans and queer youth (Andrzejewski et al., 2020). Uncovered through a review of thirty-two existing sexual and reproductive health sites, the use of aggregate terms elides important nuances of specific experiences. For instance, sexual and gender minority as a category does not fully reveal the sexual and reproductive health needs of a female-to-male trans person. Further, online platforms balance messaging based on risk versus affirmation, revealing the tensions between highlighting the importance of practicing specific health behaviors to reduce risk and normalizing actions to diminish shame. Sexual and reproductive health platforms also face difficulty in presenting information for trans and queer youth *specifically* compared to knowledge for anyone generally. These results indicate that designers of sexual and reproductive health platforms for trans and queer youth must consider how to frame content—as in risk and affirmative and specific and general—and avoid conflating aggregated groups and needs within the trans and queer umbrella.

2.2 LGBTQ Youth Online

To understand the changes happening in their bodies and how to navigate developing sexualities and their social implications, many trans and queer teens go online to find information (Schimmel-Bristow & Ahrens, 2018; Fox & Ralston, 2016). While some online resources can provide relevant information, many are often unvalidated, unmoderated, and some also spread misinformation (Haley et al., 2019). Participants in one particular study described a shared experience of finding a new sexual health resource only to realize that it was encouraging gender dysphoria and projecting many values parroted by trans-exclusionary radical feminists (TERFS) and other transphobic ideologies (Liang et al., 2020).

Despite their potential dangers, online spaces are also useful testing grounds for many trans and queer youth, allowing them to explore their identities, seek information, and connect with others (Faulkner & Lannutti, 2016; Fox & Ralston, 2016; Gridley et al., 2016; Mitchell et al., 2014; Schimmel-Bristow et al., 2018). Haimson argues that Tumblr *was* a queer and trans technology because it brought together themes vital to the queer and trans experience: ”temporality, openness, change, separation, realness, intersectionality, and erotics” (Haimson et al., 2021, pg 354). Haimson et al. expands upon this further by stating that “a trans technology must embrace the materiality, multiplicity, fluidity, and ambiguity that lie at the heart of transgender experiences” while also pointing out that a technology can embody all these values and still not be designed for trans people (Haimson et al., 2021, pg 357).

Given research demonstrating that trans youth tend to use online spaces as resources, there is ample opportunity to identify the design needs of such technologies and specific ways trans and queer youth can digitally engage with sexual health topics. However, one overarching barrier to bringing more youth online to learn about sexual health are the organizational and legal policies that can prevent queer users from ever accessing this content. At the platform level, the policy changes to Tumblr’s move towards “a better, more positive Tumblr” equated to banning all “adult” content, a move that impacted sex workers, artists, and queer and trans users (Craven, 2018; Haimson et al., 2021). Instagram has a similar history of censoring and suppressing any content that even suggests sexuality, a move that has impacted many queer users and artists (Joseph, 2019; Noronha, 2019). There has also been a global governmental push to restrict online content including the Digital Economy Act from the United Kingdom, FOSTA-SESTA from the United States, and the Online Safety Bill in Australia (Badge, 2021; Romano, 2018). A common thread throughout these legislations is the regulation of sexually suggestive content through the guise of online safety, which calls for questioning who gets to feel safe and who does not. Embedded across many of these calls for safety are paternalistic urges to protect youth from ideas and impulses that can lead to “dangerous” outcomes. However, in writing about the online, social lives of teens today, danah boyd points out how these sheltering tactics can actually hinder youth from forming their own opinions about the world around them and their own identities (boyd, 2014). Following this line of thinking, and as other scholars have pointed out in the past, adults are quick to shield youth from the complexities of the world, determining what is and is not appropriate for youth *on their behalf*. And yet, boyd suggests that teenagers have and will continue to find a way to learn from the online worlds, regardless of the barriers we place in front of them.

Furthermore, experts in youth and their online privacy actually frame navigating online safety as part of the developmental and growth process. Similar to the arguments against abstinence-based sex education, these scholars agree that a total prevention of “risky experiences” is both unrealistic and can actually hinder the possibility of positive outcomes. In this case, Wisniewski and colleagues have found that exposure to lower risk online experiences can “develop crucial interpersonal skills, such as boundary setting, conflict resolution, and empathy” (Wisniewski et al., 2016, pg 3919). Through this lens, designers of online experiences for youth should prioritize resilience and guiding youth to be prepared for what they might encounter, rather than striving for total control and prevention.

Research examining the LGBTQ youth’s sexual health information needs have surfaced several lessons and complications. In particular, Delmonaco and Haimson make a case for integrating social media platforms into LGBTQ-specific sexual health information resources by showcasing how social media sites, even those unrelated to sexual health, act as a starting point for sexual health information seeking for LGBTQ youth (Delmonaco & Haimson, 2022). Passive encounters with sexual health topics through platforms like YouTube, Tumblr, and fanfiction sites led to more intentional online information seeking for sexual health guidance. The authors also point out that social media is conducive to sharing lived experiences related to sexual health, positioning it as an impactful lever towards current information seeking practices (Delmonaco & Haimson, 2022). However, content moderation is an obstacle for social media-based sexual health interventions. Online platforms have a long reported history of inequitable experiences with content removal for marginalized people (Haimson et al., 2021; Haimson et al., 2021). Any mention of trans experiences with sexual health can be marked as adult content and thus get removed even if the subject matter is in accordance with platform guidelines (Haimson et al., 2021). As such, new social media platforms must examine how they will handle moderation of trans and queer content.

2.3 Designing with Youth through Participatory Methods

Given boyd’s point that youth are capable of forming their own opinions on their own, adults should work with rather than against them. This concept can extend into the design of new worlds; for example, through the technologies that youth interact with to the strategies for addressing youth-specific health equity issues.

Research *with* youth presents a unique set of challenges, such as access barriers and communication struggles, but focus groups have proven to be one method for effectively engaging with adolescents because they work to rebalance power dynamics, among other reasons (Poole & Peyton, 2013). In both health and technology design, researchers have taken up participatory and co-design methods (e.g., Metatla & Cullen, 2018; Pitt & Davis, 2017), with some researchers developing and adapting their own techniques. For example, Walsh et al. introduced Line Judging in which participants position themselves on a line drawn on the ground to reflect their positive or negative preferences for an idea or topic (Walsh et al., 2013). Line Judging allows participants to express opinions on a spectrum, spatially visualize their choices, and explain to researchers their rationale for choosing their positions. Additionally, Guha et al. presented the Mixing Ideas method for collaborative brainstorming (Guha et al., 2004). These methods have been instrumental in developing insights into a wide array of topics such as identity formation (Coenraad et al., 2019) and cyberbullying interventions (Ashktorab & Vitak, 2016).

Researchers have also used participatory design methods to engage with marginalized youth such as teens who are immigrants (Fisher et al., 2014), Syrian refugee youth (Fisher et al., 2016), and Latina teens (Vacca, 2019). Participatory design methods are particularly impactful for the ways they enrich the work and give youth a sense of belonging and empowerment through their participation (Ryan et al., 2013). These methods have proven valuable in engaging with marginalized youth because they highlight voices and perspectives typically left out of research (Marcu et al., 2016). Scholars have further contextualized participatory design in youth-centered design work. In particular, the Cooperative Inquiry method lays out four roles that children can have in the design process—users, tester, informant, and design partner (Druin, 1999; Yip et al., 2017). By contesting traditional roles between researcher/participant and adult/youth, everyone involved in the research and design process can then negotiate where and how they are positioned. Through these values, researchers can have deeper engagements with youth participants, opening up new funds of knowledge that stem directly from the youth themselves.

Community-based participatory research (CBPR) builds upon the practices and values found in participatory design and works to transcend traditional participant-researcher power dynamics towards a more collaborative and equitable partnership (Satcher, 2005; Rappaport et al., 2008; Israel et al., 1998; Israel et al., 2003; Israel et al., 2017). Working as more than just a method and more as a research orientation, Minkler defines CBPR as "*a collaborative process that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community with the aim of combining knowledge and action for social change*" (Minkler, 2004, pg 686; Wallerstein & Duran, 2006). CBPR emphasizes mutuality in the research experience, which extends to how everyone involved benefits, the relationships developed and sustained with communities, and the embrace of co-learning together (Israel et al., 2010; Israel et sl., 2017). Because of this intentional effort to work with communities towards generating solutions that work for them, these methods elicit more sustainable, community-centered, and self-reliant outcomes (Rappaport et al., 2008). Additionally, the method's investment in distributing power in the research process is particularly important in addressing the academic research's historically exploitative relationship with other communities, including communities of color, low-income, and trans and queer people (Minkler, 2004; Minker & Wallerstein, 2008; Gamble, 1997; Koster et al., 2012). CBPR has been particularly successful in addressing health equity because of the ways it works towards more systems-level interventions like policy changes (e.g., Freudenberg et al., 2005; Minkler et al., 2008; Themba-Nixon et al., 2008; Vasquez et al., 2006; Vasquez et al., 2007).

However, CBPR is not without its own challenges, and despite a researcher's best intentions to be equitable in their methods, actually doing so is less clean and clear. To this end, Minkler identifies a number of challenges to ethically carrying out CBPR methods: 1) actualizing a truly "community-driven" agenda is difficult due to outside influences (e.g., a dissertation); 2) insider-outsider tensions exist based on imbalances in benefits and resources; 3) internalized racism and other forms of bias manifest despite a researchers' best intentions; 4) unstable conceptualizations of what "community" and "participation" entail; 5) unclear expectations for the findings and outcomes (Minkler, 2004). An additional complexity to CBPR research is that the needs of a community, project, and process are contextually-dependent; what might work in one partnership might not uniformly transfer to another (Israel et al., 2017).

In HCI research, CBPR has become more widely adopted as researchers have taken up calls to address equity and justice and shift focus from individuals to communities, leading to rich insights into design-based community partnerships (Ogbonnaya-Ogburu et al., 2020; Dombrowski et al., 2016; Cooper et al., 2022). In a systematic review of community-collaborative approaches to computing research, Cooper and colleagues identified overlapping tensions with those enumerated in the previous paragraph, namely around addressing mutual benefits, sharing control of project directions, and establishing trustful and meaningful relationships with community partners, among others (Cooper et al., 2022).

Building off traditions from PD and Action Research (Ghoshal & Bruckman, 2019; Hayes, 2011), the conversation around participatory methods in HCI has recently undergone valuable critiques. Focused on questions like "who gets to participate in design and computing research and why?" scholars have highlighted the importance of better understanding communities that

HCI researchers partner with and how design might counter oppressive norms (Harrington et al., 2019). In particular, Erete et al.'s "intersectional analysis of power" involves identifying a community's contextual histories of exploitation and violence and reforming how researchers engage with communities accordingly (Erete et al., 2022). Doing so, as the authors point out, challenges a design paradigm that values neutrality, whiteness, novelty, and capitalism (Erete et al., 2022). Irani has uncovered how standardized design approaches, known as "design thinking", can actually uphold structures of oppression in the ways that it cherishes innovation and profit (Irani, 2018). Harrington and coauthors have additionally distinguished how privilege is engtangled in approaches to design thinking and call for deeper reflections on how researchers can either continue and/or challenge cycles of oppression (Harrington et al., 2019).

Participatory methods, including PD and CBPR, have been impactful in involving young people in the design of new youth-centered technologies, and these forms of engagements have led to valuable insights into how young people want to experience technology. Ghosh and colleagues have taken this up in their approach to understand childrens' perceptions of parental control apps, finding that teens valued having agency in their own online safety (Ghosh et al., 2018). As scholars like Ghosh and Wisniewski have shown, engaging young people in the design process can lead to more effective and relevant ways of addressing important matters like online safety (Wisniewski et al., 2016; Wisniewski et al., 2017). There has additionally been recent work to involve youth to develop online tools for mental health and minority stress (Bhattacharya et al., 2019; Bauermeister et al., 2022). To this end, this previous body of work calls for more youth-centered approaches that redistribute power towards youth in the design of their technological futures, a challenge I take up in this dissertation.

2.4 Theoretical Foundations

This work draws from three overlapping areas: queer theory, systems of oppression, and intersectionality. Working from these theoretical foundations has shaped my overall understanding of power and resistance from three different levels—individual, communal, and structural (Collins, 2022; Combahee River Collective, 1983). My own theoretical stance stems from a legacy of scholars of Black women, queer and trans people, people with disabilities, and others with commitments to justice in both their research and activism.

2.4.1 Queer Theory

Queer Theory is grounded in foundations of queerness and sexuality, but it also provides insight into social power dynamics at large. It is perhaps the ouroboros of theories, a snake swallowing its own tail, in its paradoxical nature. Queer theory defies a clear definition, but being able to reason through such complexity is what helps shed light upon the intricacies of social power.

Previous scholars have described queerness both as an identity category and a political stance towards subjugation and resistance. Halperin characterizes queerness as “whatever is at odds with the normal, the legimate, the dominant. There is nothing in particular to which it necessarily refers. It is an identity without an essence” while Kemp adds that “Queer, if it names anything, names a critical impulse that can never, must never, settle (Halperin, 1997; Kemp, 2009). Building off of these conceptualizations, two principles that I have derived from the canon of Queer Theory guide this dissertation as they help to reshape design practices: challenging and expanding norms and promoting personal autonomy towards liberation.

Principle 1: Challenging and Expanding Norms

Previous work has explored how challenging norms through a Queer Theory approach can inform enactments of design thinking (Cox, 2018; Moeggenberg & Walton, 2019). Cox describes a shift in pedagogical norms to embrace experiences that are culturally thought of as failures, as he writes that "chaos, failure, and disruption are not only productive; they are desirable as a permanent state” (Cox, 2018, pg 291). Here, Cox’s assertion about the productivity of failure is reminiscent of Judith Halberstam’s own thesis on failure where she writes that “under certain circumstances failing, losing, forgetting, unmaking, undoing, unbecoming, not knowing may in fact offer more creative, more cooperative, more surprising ways of being in the world” (Halberstam, 2011, pg 2-3). Moeggenberg and Walton additionally challenge the notion of time by pointing out that common design thinking practices put forward time constraints that designers do not have to be bound by (Moeggenberg & Walton, 2019). By reconsidering why these time constraints exist, the authors argue that “one benefit to interrupting the typical temporal performances of design thinking is that it helps us continue to maintain design goals in service to the user” (Moeggenberg & Walton, 2019, pg 7). This way of thinking elucidates that time constraints in design thinking are human-made and thus can be adjusted to fit the needs of a specific project or community partner.

The principle of challenging norms can also lead to more expansive, fuller understandings of human experiences which allows for more practical and effective design interventions. For instance, there have been debates in CBPR work revolving around the question of what defines a community? In an ideal sense, community signals political, experiential commonality, or a sense of ‘home’. However, this line of thought makes assumptions of communal uniformity that often does not exist in a way that can be counteractive. As Queer Theory scholar Nikki Sullivan writes, “such a notion of community cannot tolerate difference” (Sullivan, 2003). Reorienting an understanding of community around what makes a group different from each other, rather than identical, means that community is never a given or a guarantee. Instead, community is something that is built and sustained with intention to work through differences.

As I wield the concept of community in my dissertation, I understand it from this Queer Theory lens that shifts the focus onto difference and how the negotiation of such difference can reshape community boundaries. This act of communal mediation aligns with the values emphasized in an CBPR approach. Sullivan also writes that “community, in this sense, rather than denying or covering over differences in the service of unity, is the experience of the impossibility of communion, the experience of radical difference. [...] it is an unworking which fractures the humanist myth of oneness and allows for the recognition of irreconcilable but productive differences, and the debates generated in and through these” (Sullivan, 2003). Put into design practice, researchers cannot assume that any community (e.g., trans and queer people) coexist as one, fixed grouping with the same set of needs and design preferences. In addition, Halberstam outlines how an expansive mindset “allows us to escape the punishing norms that discipline behavior and manage human development” (Halberstam, 2011, pg 3). Challenging norms calls for researchers to remain attentive to and explore nuance and allows designers to be more accepting of and attuned to the messy and varied nature that make us human.

Principle 2: Promoting Personal Autonomy Towards Liberation

Queer Theory is not limited to sexuality and sexual practices; it extends outwards into the social dimensions of everyday life (Sullivan, 2003). As a whole, the project of Queer Theory works by interrogating the political nature of sexuality to provide a gateway into wider conversations around networks of power. Berlant and Warner write that a queer commentary on sexuality “sees intimate sex practices and affects as related not just to family, romance, or friendship but also to the public world governing both policy and everyday life. [...] Queer commentary has tried to challenge some major conditions of privacy, so that shame and the closet would be understood no longer as isolation chambers but as the architecture of common culture” (Berlant & Warner, 1995).

As such, a large body of work has focused on the fight for personal autonomy, taking on the divisions between public and private spaces and what is socially permissible (Foucault, 1990; Anderson, 2012; Berlant & Warner, 1998). Within this exchange there are debates over who has power to govern, punish, and set standards for people. Here, bodies are both a site for political power struggle and a place of resistance (Foucault et al., 2008). Jeffrey Weeks writes that “the history of sexuality is inextricably intertwined with structures of power. [...] There are patterns of domination, hierarchy, regulation, and multiple subjectivities and forms of agency – individual and collective. Which is why sexuality, and its history, are always necessarily political” (Weeks, 2016, pg 3-4). Agency, then, is complicated by “the existence of multiple narratives” because such variability makes governance difficult; thus, Weeks goes on to write that “sexuality is inevitably and always enmeshed in the coils of power relations, but rejects overarching determinants, and stresses the vivacity of collective and personal agency” (Weeks, 2016, pg 8).

In this dissertation, queerness is a destablizing concept used for identifying any norms and assumptions found in the design process that prevent individual autonomy and impede paths towards liberation. Much like Moeggenberg and Walton have questioned and pushed back on time constraints of traditional design thinking, my dissertation works to first recognize counterproductive norms and false binaries and then reform the conditions to better support situational needs.

2.4.2 Systems of Oppression and Design Justice

To first situate marginalization more broadly, we provide a brief overview of three conceptualizations of systems of power. Each shows how a greater system of oppression is made up of numerous, interlocking, hegemonic components (e.g., racism, homophobia, transphobia). They further demonstrate that an individual's power is uniquely made up of their different identities and experiences that afford them privilege and/or discrimination and differ from context to context.

Coloniality of Power. Introduced by decolonial scholar Anibal Quijano, the coloniality of power is the basis for social classifications and social discriminations in modern Western society (Quijano, 2000). While initially used to describe European colonialism in Latin America, the concept has been applied to colonialism more globally. Scholars like Catherine Walsh have explored social classifications based on differences of race, sex, gender, and who is considered human versus non-human, among others (Lugones, 2007; Mignolo, 2016). As Mignolo points out, this classification system can be understood as a matrix, as each category interweaves social determinants of an individual's place in society and how they are treated (Mignolo, 2016). Like modern systems of oppression, the coloniality of power is not a natural occurrence, but a human-made system of control and domination based on socially constructed categories. It is also the basis for white supremacist social cultures and norms of today.

Axes of Oppression. In reflecting on their experience as an educator, Morgan created a grid to visually represent a person's intersecting axes of privilege, domination, and oppression. In this grid, Morgan labels "domination" on the horizontal axis, "privilege" above, and "oppression/ resistance" below (Morgan, 1996, p.107). According to Morgan, each person (specifically, each North American person) is positioned along specific axes that cross two quadrants, which include young to old, heterosexual to LGBTQ+, white to Black Minority Ethnic people, Anglophones to English as additional language, and more. Morgan writes that “this point is simultaneously a locus of our agency, power, disempowerment, oppression, and resistance” and highlights the necessity for “both awareness and honesty with respect to our own positioning on the various axes of this grid” (Morgan, 1996, p.107).

Matrix of Domination. Black feminist scholar Patricia Hill Collins introduced the matrix of domination to describe how systems of race, class, and gender have worked together to shape the lived experiences of Black women, while also noting that there are additional dimensions for others (Collins, 2002). At the same time, individuals can face oppression and/or receive benefits depending on their position in the matrix. Collins also identified three levels “as sites of domination and as potential sites of resistance”: the personal, community, and institutional levels (Collins, 2002, p. 557). In Design Justice: Community-Led Practices to Build the Worlds we Need, Costanza-Chock contextualizes each level in design and different opportunities for domination and/or resistance within design justice (Costanza-Chock, 2018). The personal level in design justice, which refers to individual experiences that can be both freeing and controlling, might manifest in how design decisions affect different people. The community level refers to identifying groups of people who have shared experiences, and one instance is how platform design can support some communities while putting down others. As an example, Costanza-Chock cites Gillespie as she brings up Facebook’s inaction to take down “white nationalist” posts, thereby assisting white nationalist groups at the expense of targets of the hate group (Costanza-Chock, 2018; Gillespie, 2018). Costanza-Chock also identifies design institutions for Hill’s third, institutional level, including funding agencies like the National Science Foundation or the Department of Defense, academic institutions that teach designers, and companies like Google, Apple, or Microsoft. These three frameworks—coloniality of power, the axes of oppression, and the matrix of domination—help to characterize how an individual's position of oppressor and oppressed can reproduce a larger system of domination. Hill suggests two ways to resist domination: through individuals identifying how they reproduced domination themselves based on their position on the matrix and by rejecting beliefs that further oppression (Collins, 2002).

2.4.3 Intersectionality

Kimberlé Crenshaw has been historically recognized as the first to document intersectionality, highlighting how people face additional dimensions of structural oppression specific to the multiplicity of their marginalized identities (Crenshaw, 1991). Crenshaw described how a system with a singular focus on race or gender erases those who have identities that intersect between the two—Black women specifically—and excludes their experiences of oppression in common pursuits of justice (Crenshaw, 1989). In HCI, intersectionality has become an increasingly popular analytical tool for better understanding complex identities (Rankin & Thomas, 2019). In particular, Schlesinger et al.'s introduction of Intersectional HCI calls for the HCI community to collectively better attend to the array of identities both participants and authors may hold (Schlesinger et al., 2017). Since its publication, several scholars have both extended and critiqued HCI's relationship with and use of intersectionality as an analytical lens. Wong-Villacres et al. recommended extending the scope of intersectionality to go beyond individual user identities and instead focus on "interacting processes" to better understand how an individual's identities are socially manifested (Wong-Villacres et al., 2018, p. 48). Further, Rankin and Thomas call for "a cultural shift within the HCI community, one that goes beyond intersectionality as a buzzword to instead embrace equity, inclusion, and social justice as the new standard" (Rankin & Thomas, 2019, p. 64). Collins and Bilge challenge researchers to use intersectionality as a way of understanding intersectional-minded awareness and practice, rather than getting entirely stopped by identity politics (Collins & Bilge, 2016). They write that HCI’s co-option of intersectionality is not only ahistorical in the ways it ignores how conversations around intersectionality have long been about, for, and by Black and Brown women, but also continues to ignore and discredit the role that Black women have played in research. Finally, Erete et al. offered another approach to intersectional HCI research: adapting research methods to better meet the needs of underserved communities and calling for better attending to contextual differences, self-reflection, and embracing dissent in the research process (Erete et al., 2018). Keeping these points in mind, we scoped this study through an intersectional lens: examining HCI researcher’s relationships with many forms of marginalization, without prioritizing any one specific axis of oppression.

Chapter 3. Embracing Four Tensions in HCI Research with Marginalized People

In the early stages of my doctoral research, I came to the conclusion that working with marginalized people was important to me. Seeking out guidance for the best practices of working with marginalized people, I hoped that if someone had written a checklist or a how-to guide, then I could guarantee that I was doing my work as equitably as possible. I considered the role that identity plays in research with marginalized people, questioning "can someone from a non-marginalized population do research on marginalized people?" and "how can we know if we are making the "right" decision in research, versus a "good" or well-intentioned one?" Through this questioning, I set out on an exploratory study into how marginalization and HCI intersect and develop a theoretical framework to inform my future methods. This manuscript was written in collaboration with Dr. Sean Munson and Dr. Julie Kientz, and as such, I use we through this chapter. However, I acted as lead author and writing is most reflective of my own analysis and position (Liang et al., 2021).

3.1 Introduction

The world is going through a sociotechnical reckoning. The injustices that are embedded in the frameworks of our society and how they disproportionately harm groups of people who society has long pushed to the margins are finally becoming centered in Human-Computer Interaction (HCI). In 2019, Ruha Benjamin introduced "the New Jim Code" which describes how new technologies can perpetuate the very social inequities they promise to solve, demonstrating that computing, design, and academic spaces are not exempt from this critical conversation (Benjamin, 2020). Indeed, there are numerous examples of these extensions of oppression and control into computing, and several scholars have shown how racism, sexism, ableism, homophobia, transphobia, and countless other systems of oppression are and have been integrated into our technical systems and cultures (e.g., Hankerson et al., 2016; Hoffman, 2019; Keyes, 2018; Waller, 2020; To et al., 2020). Google Photos algorithmically labeling images of Black people as “ape” and “gorilla” provides just one example, though there are many more instances of technology supporting policing, discrimination, and violence (Hankerson et al., 2016). As a result, the debate whether artifacts do in fact have politics or whether technology is neutral should be closed for good (Winner, 1985).

Within the field of HCI, scholars are coming to an agreement that deeper engagement with marginalized people should be a serious priority for researchers (Bardzell & Bardzell, 2011; Cahill, 2007; Harding, 1992; Harding, 2004; Muller, 2003). As a result, HCI scholarship has increasingly shifted its efforts to working with these groups. HCI researchers have centered groups of people who have faced (and constantly face) racism (e.g., Grimes & Grinter, 2007; Harrington et al., 2019; Harrington & Piper, 2018; O’Leary et al., 2019; To et al., 2020), ageism (e.g., Brewer, 2017; Cornejo et al., 2016), sexism (e.g., Haimson et al., 2020; Scheuerman et al., 2018), ableism (e.g., Bennett et al., 2018; Brulé & Spiel, 2019), classism (e.g., Le Dantec & Edwards, 2008; Dillahunt & Veinot, 2018; Siek et al., 2009; Strohmayer et al., 2015), and colonialism (e.g., Smith et al., 2020; Dye et al., 2017). Further, matters of ethics and inclusion in research also affect fellow researchers, as there are people in the HCI research community that both experience marginalization and are surrounded by research that involves marginalized people (Erete et al., 2020; Ymous et al., 2020). Given the complexity of interweaving personal identity and science, there is still much work to be done. While some scholars have carved out research agendas like Social Justice HCI, Feminist HCI, and Intersectional Computing (Thomas et al., 2018; Dombrowski et al., 2016; Bardzell & Bardzell, 2011), many researchers working with marginalized people or collaborators who experience marginalization themselves may be left wondering if and how to proceed and face difficulties in actively reflecting on their role in such research.

At a high level, marginalization refers to how a person experiences the world around them based on their identity and how others perceive them. For those who experience marginalization, there are different contexts in which they are marginalized and/or privileged, and their experiences can change over the course of a day, a year, or a lifetime[3]. Marginalization can range from everyday microaggressions to matters of life and death to the development of systems that keep entire groups of people down. Understanding how marginalization works also requires identifying the structural powers that do the actual marginalizing (Veinot et al., 2019). The oppression that marginalized people face is not a natural or individual occurrence but, rather, an active operation through various, intertwining processes. For those who do research with marginalized people, Sara Ahmed points out that treating these groups as “Other” without awareness of the powers that have done the actual suppressing is ethically irresponsible (Ahmed, 2012).

In talking about marginalization, we wish to be intentional with our language. Terms often associated with marginalized people like underserved, underrepresented, or minorities all denote themes of being forgotten and left out by larger society (Dutt-Ballerstadt, 2020; Vines et al., 2013). Others have described marginalized people as vulnerable; however, there are issues with framing groups of people as weak, in need of help, and burdensome (Vines et al., 2014; Waycott et al., 2015). In considering these phrases, we align ourselves with previous criticisms of these terms and view marginalization as a failing of society, rather than a failing of any individual person. Further, when talking about researchers who experience marginalization

---

[3] We thank Dr. Alexandra To for helping us craft this understanding of marginalization.

throughout this paper, we interchangeably use “researchers who experience marginalization” and “marginalized researchers” to discuss one part of a person’s identity without framing it as their entire experience. This specific nuance speaks to a broader tension in this paper of focusing on marginalization without simplifying a person’s identity down to the oppression they face.

An intersectional approach to research means that social justice efforts cannot operate as either/or decisions in who gets centered. In our alignment with an intersectional research paradigm, we approached our research question with the following understanding of Hancock’s “categories of difference:” that we should address more than one category, single categories should not be compared and prioritized without the consideration of others, and both individual and institutional factors influence these groups (Hancock, 2007). Looking across these categories of difference and marginalization, we set out to answer the primary research question of: RQ 3a. How do HCI researchers engage in and reflect on research with marginalized people? As research progressed, we also identified three interaction-based research questions to examine individual and institutional influences:

> RQ 3b. How do HCI researchers see their research affecting participants, and how do they reflect on and adjust their practices as a result?
>
> RQ 3c. How do HCI researchers engage in and reflect on research with marginalized people as it affects researchers?
>
> RQ 3d. How do the norms of the field of HCI affect marginalized people as researchers and, further, those researchers’ interactions with participants?

As attention to research with marginalized groups grows, we pursued this work to learn how we might avoid interest convergence in HCI, defined by Ogbonnaya-Ogburu and colleagues as a selfishly-motivated, surface-level form of inclusion that ultimately benefits those in power (Ogbonnaya-Ogburu et al., 2020). More specifically, we sought to understand what current HCI researchers do to carry out research with marginalized people, rather than for and only for researchers and institutions. We draw upon the stories, lessons, and concerns from 24 HCI researchers through survey responses and interviews so that the HCI community might build collective knowledge, learn from their reflections, and recognize whether and how to best move forward. Notably, participants in this study were predominantly based in the United States, despite our efforts to recruit more broadly.

We offer a critical, reflective resource for HCI researchers who wish to better their own practices: researchers who engage with marginalized people in their work and researchers who do not want to exclude marginalized people in their work. Our research outlines four tensions which our audience must embrace: *exploitation, membership, disclosure,* and *allyship*. These tensions are interlinked and look across marginalization as a whole. Positioning these as tensions, we highlight that a complete resolution may not be possible in this form of work, and yet there is value in continuing forward. As Haraway demonstrated, it is critical to think through issues even where there can be no clear path to a resolution (Haraway, 2016). These tensions relate to Rittel and Webber's "wicked problems" in the ways that they are circular social issues, are technical approaches constrained by legal and social policies, and lack a definitive end (Rittel & Webber, 1973). Our hope is that everyone can benefit from reflecting upon these four tensions, even those already taking steps to avoid unethical practices. For example, researchers using participatory or human-centered design methods does not mean they have guaranteed equity (Harrington et al., 2019).

Our motivation in this chapter is not to say who can do what research but, rather, to highlight that if researchers choose to engage with marginalized people in their work, there are several key questions around each tension that require reflection and discussion. In addition, we describe researcher- and field-level influences on research involving marginalized people and reflect on how HCI needs to evaluate how it structurally disfavors marginalized participants and researchers alike.

In this paper, we make the following contributions:

1. We provide an empirical account of the lived experiences of researchers in HCI. Most of the participants of this study self-identified as having one or more marginalized identities, so we also prioritize and center their experiences in conversations about research with marginalized people in HCI.

2. We lay out four tension areas that we urge researchers to consider, discuss, and personalize based on their own specific work, describing the complexity involved in each and what steps researchers can take to embrace each one.

3. Drawing upon the lived experiences of these HCI researchers and literature from activists, we put forth an allyship-oriented approach to navigating these tensions in research with marginalized people, providing a call-to-action for the HCI community.

4. We leave room for and encourage further exploration into this topic, as this work is not meant to be–nor can it be–an instruction manual to research with marginalized people.

3.2 Related Work — HCI and Marginalized People

Our work builds upon HCI research's historical involvement with marginalized people, one that has more recently engaged in deeper ethical discussions about how to best conduct research. We present an overview of such discourse and describe several concepts close to the heart of this work—intersectionality, reflexivity and positionality, membership, equity and justice, and impact.

HCI has seen a growing body of work both in building tools, services, and knowledge for the perceived benefit of marginalized people and in the meta-discourse of doing this kind of research. A review of over thirty years of HCI research showed how HCI scholars have historically neglected users who might have multiple marginalized identities, but recent years have seen an upward trend towards greater awareness (Schlesinger et al., 2017). As many scholars have demonstrated, design and HCI are inherently political, and both have the ability to rework social power imbalances (Keyes et al., 2019; Costanza-Chock, 2018). As a result, HCI researchers have made many efforts using their skills and expertise to promote social justice efforts. The agenda of HCI research involving marginalized people is extensive, including building tools that attempt to help people. Examples of this include Le Dantec et al.'s system that better connected staff and residents at a shelter for homeless mothers and exposing the potential dangers of technology, such as the ways that facial recognition systems can bring harm to transgender and non-binary people (Le Dantec et al., 2011; Keyes, 2018; Scheuerman et al., 2018). Others have contributed commentary on the ways in which scholars do HCI research. As Baumer & Silberman wrote, "when we do build things, we should engage in a critical, reflective dialog about how and why these things are built" (Baumer & Silberman, 2011, p.2274). Waycott et al. identified challenges such as protecting the privacy of participants and considering how technology might have adverse consequences for those we design for (Waycott et al., 2015). Researchers have also developed frameworks in thinking about when not to turn to technology (Baumer & Silberman, 2011), social justice-oriented commitments for researchers (Dombrowski et al., 2016), and how we conceptualize and design for "vulnerable" populations (Vines et al., 2013).

3.2.1 Marginalization in the Context of HCI

As part of the "third wave" of HCI, many researchers have explored how HCI can learn from feminist values (D'Ignazio et al., 2016; Fiesler et al., 2016), drawing from a key characteristic of resisting oppressive power structures through individual and collective action (Thompson & Reinharz, 1992). Many have taken up calls to include those marginalized by these systems and explored how such expanded involvement can actually improve HCI knowledge. As Bardzell & Bardzell wrote, "turning to the experiences of the marginal is not only ethical, in the sense that it empowers a comparatively powerless population to participate in processes of social control, but it is also *good science*, because it introduces the potential for empirically derived insights harder to acquire by other means" (Bardzell & Bardzell, 2011, p.678).

Further, the growing area of action research directly interfaces with the political by working to rebalance power dynamics (Williamson & Prosser, 2002). In particular, Hayes outlined how action research and HCI are related, emphasizing research with people, not for or about or focused on, transferability rather than generalizability of findings, and that researchers avoid abruptly leaving study sites without helping participants become self-sustaining (Hayes, 2011). Action research, however, is still an imperfect solution. Williamson & Prosser have raised that the goals of action research (e.g., creating a space for open disclosures) sometimes compete with common ethical research practices, because they do not maintain confidentiality and anonymity, make informed consent difficult, and/or do not protect participants from harm (Williamson & Prosser, 2002).

Over the years, HCI researchers have strived to understand what to design, whether to design, why (and why not) we design, and who we are designing for. Discourse around work that involves marginalized people is rich and healthy in the ways it has benefitted from a constant cycle of self-reflection and critique as a collective field. Below we outline several common themes across research involving marginalized people: intersectionality, reflexivity and positionality, membership, equity and justice, and impact. With the final three, we borrow lessons from within HCI and from fields adjacent to HCI that have engaged in meta-critiques of their own work that provide ample inspiration for the greater HCI community to follow. While we review a range of fields—Disability Studies, Community-Based Participatory Research (CBPR) and Participatory Design (PD), and Information and Communication Technologies for Development (ICTD)—we depict only slivers of a much greater body of knowledge.

3.2.2 Intersectionality

Kimberlé Crenshaw has been historically recognized as the first to document intersectionality, highlighting how people face additional dimensions of structural oppression specific to the multiplicity of their marginalized identities (Crenshaw, 1991). Crenshaw described how a system with a singular focus on race or gender erases those who have identities that intersect between the two—Black women specifically—and excludes their experiences of oppression in common pursuits of justice (Crenshaw, 1989).

In HCI, intersectionality has become an increasingly popular analytical tool for better understanding complex identities (Rankin & Thomas, 2019). In particular, Schlesinger et al.'s introduction of Intersectional HCI calls for the HCI community to collectively better attend to the array of identities both participants and authors may hold (Schlesinger et al., 2017). Since its publication, several scholars have both extended and critiqued HCI's relationship with and use of intersectionality as an analytical lens. Wong-Villacres et al. recommended extending the scope of intersectionality to go beyond individual user identities and instead focus on "interacting processes" to better understand how an individual's identities are socially manifested (Wong-Villacres et al., 2018, p.48). Further, Rankin and Thomas call for "a cultural shift within the HCI community, one that goes beyond intersectionality as a buzzword to instead embrace equity, inclusion, and social justice as the new standard" (Rankin & Thomas, 2019, p.64). Collins and Bilge challenge researchers to use intersectionality as a way of understanding intersectional-minded awareness and practice, rather than getting entirely stopped by identity politics (Collins & Bilge, 2016). They write that HCI's cooption of intersectionality is not only ahistorical in the ways it ignores how conversations around intersectionality have long been about, for, and by Black and Brown women, but also continues to ignore and discredit the role that Black women have played in research. Finally, Erete et al. offered another approach to intersectional HCI research: adapting research methods to better meet the needs of underserved communities and calling for better attending to contextual differences, self-reflection, and embracing dissent in the research process (Erete et al., 2018). Keeping these points in mind, we scoped this study through an intersectional lens: examining HCI researcher's relationships with many forms of marginalization, without prioritizing any one specific axis of oppression.

3.2.3 Reflexivity and Positionality

One popular belief in Western Feminism is Standpoint Theory, which acknowledges that an individual's experiences and background make up a unique perspective on the world (Franks, 2002; Harding, 2004). Because of this, a researcher's identity influences how they interact with participants (Harding, 2004; Brulé & Spiel, 2019), and so it is an important consideration in work that involves marginalized people, especially in the ways we share findings. In research, reflexivity and positionality work to oppose a dominant claim in science of objectivity by acknowledging and, at times, identifying potential researcher bias. Reflexivity calls upon researchers to self-reflect and understand their own possible biases, their role in power relations, and how these factors might manifest in their work (Moss et al., 1999). Positionality is only slightly different in that it addresses how a researcher's perspective compares to others' perspectives (Franks, 2002). In practice, positionality has led researchers to openly discuss how their own positions based on their race, class, gender, and other social/power categories may influence their work (England, 1994; Hopkins, 2009). In HCI, many scholars have called for improved reflexivity practices, specifically researchers evaluating the ways in which their identities influence their work (Dombrowski et al., 2016; Malinverni & Pares, 2017; Schlesinger et al., 2017). Taylor stressed the importance of researchers first reflecting on their own positions and how they might influence the solutions they are pushing forth before analyzing participants and what is "out there" (Taylor, 2011).

Positionality, or perceived positionality, can also affect how readers receive researchers and their work, and some scholars have pointed out that knowledge from marginalized people is unfairly judged. Fricker's epistemic injustice, specifically testimonial injustice, occurs when people question or diminish knowledge because of the identity or identities of the person it came from (Fricker, 2007). Berenstain built on this by defining epistemic exploitation as putting the responsibility to educate the majority on the marginalized people themselves, a process that places an emotional burden on them, is often taken for granted, and goes uncompensated (Berenstain, 2016). These perspectives are crucial in calling out the double standard for knowledge production by marginalized people—the responsibility to do so is theirs to bear while simultaneously undervalued.

Additionally, it is important to distinguish what previous scholars have meant when suggesting author reflexivity. For some, reflexivity refers to self-disclosure of the authors' identities and/or epistemological backgrounds to create more transparency in the presentation of the work (Bardzell & Bardzell, 2011; Erete et al., 2018; Schlesinger et al., 2017). Others use reflexivity as a passive tool for authors to critically reflect (Moon & Blackman, 2014; Peshkin, 1988). While both practices have their place, the first is especially important to contest under the pretense of epistemic injustice and exploitation. We drew upon this understanding of reflexive and positionality practices to shape our interview and survey protocols, with the intent of examining if, how, and what authors choose to disclose about themselves.

3.2.4 Understanding Membership through Disability Studies

Membership in a group typically entails that those within the group have shared or similar experiences or goals (Harris, 1995; Tanis & Postmes, 2005). In Disability Studies, researchers have long sought to understand the social divisions around the social construction of disability and its political impacts (Linton, 1998). Discourse around insider-outsider tensions is one particularly relevant example: scholars have debated who gets to claim membership as a disabled person, who does not, and, further, who gets to study disability. These debates are complicated by the fact that not all disabilities are obvious, referred to as "invisible," or that some might be considered "not disabled enough" (Schalk, 2013; Lightman et al., 2009; Caldwell, 2010). One example that demonstrates the various, contested facets of disability is chronic illness; the disability community has had a tepid relationship being associated with medicalized illnesses while many people are disabled by their chronic illnesses (Wendell, 2016). Additionally, disability as a cultural phenomenon has allowed those who are not disabled yet marginalized in other ways to identify with and derive empowerment from the movement (Schalk, 2013). Because of these nuances, Disability Studies provides a lens into the contestability of membership and highlights the difficulty in universally labeling who is a member and who is not. In this work, we examined the complexity of membership, as we saw different examples of how researchers shared and did not share membership with those they work with.

3.2.5 Understanding Equity and Justice through Community-Based Practice Research (CBPR) and Participatory Design (PD)

A large body of work already exists that focuses on social equity and justice to address social imbalances. CBPR and PD prioritize giving opportunities to those in research who may not have initially had access to them. Both fields work to shift the research paradigm from studying people to learning from and with them. By doing so, this shift serves as a way to provide equity and justice in relationships of research.

CBPR is collaborative in nature and prioritizes social change (Minkler, 2004). The field has a long history of its researchers avoiding exploiting different groups of marginalized people through equal partnerships, critical discussions of power, and engagements with policy (Cochran et al., 2008; Israel et al., 2005; Israel et al., 2010; Wallerstein & Duran, 2006). CPBR has embraced and contributed to many social justice-oriented topics and has played a strong role in health research, specifically addressing disparities in healthcare (Israel et al., 2010; Unertl et al., 2016; Wallerstein & Duran, 2006) and involving the voices of marginalized people who often are not represented in research (De Leeuw et al., 2012; Koster et al., 2012; Castleden et al., 2008). CPBR researchers have also discussed the ethics of their practices, raising several issues. Minkler outlines examples, including insider-outsider tensions (i.e., differences, often identity-based, between the researcher and participant) and challenges from translating findings into actions for change (Minkler, 2004). Last, member checking is a common practice in CBPR, and it involves sharing findings and analyses back to participants (Grieb et al., 2015). These efforts, among many others, grapple with the uneven distribution of benefits in research and attempt to rebalance this exchange.

Participatory design (PD) can be understood separately from CBPR, but we choose to frame them together to highlight their similar efforts to restore equity and justice in research practice. This has been especially clear in research that involves adolescents (Poole & Peyton, 2013). Using PD with children and adolescents can embolden youth with a sense of belonging and empowerment, but despite its best efforts, even PD is imperfect (Ryan et al., 2013). As Erete et al. described, “we find that traditional research design methods […] even those participatory in nature, at times do not match the needs of our participants, leading to questions regarding the effectiveness of these methods among certain populations. Many of these methods do not account for the challenges faced by communities that have systematically experienced discrimination due to unfair policies and social practices” (Erete et al., 2018, p.66). Furthermore, attempts to rebalance power are complicated; for one, we may not know if our attempts are working and, second, concepts of power are nuanced and difficult to ever fully account for (Gallagher, 2008). However, in PD and CBPR, power is ultimately shared and situated through negotiation between researcher and participant (Bratteteig & Wagner, 2012). From these two areas of work, we integrated values of care into our methods and our relationships with participants in this research. We also drew from collective lessons and criticisms to understand how to address equity and justice in research with the understanding that these efforts will never be perfect.

3.2.6 Understanding Impact through Information and Communication Technology for Development (ICTD)

ICTD's ethos underscores the importance of providing services and resources to developing areas, and more generally, those often left out of research (Dell & Kumar, 2016; Shrinivasan et al., 2013). This work is often interventional in nature, with careful consideration around the impact of such research through a focus on sustainability and equitable access (Wyche et al., 2015; Vashistha et al., 2018; Heimerl et al., 2013). Researchers in this field have raised questions around technological determinism and active consideration of how technologies may not always be the most appropriate solutions (Heeks, 2002; Wyche et al., 2015; Wyche & Murphy, 2012). Researchers in HCI4D, a subfield of ICTD, have also wrestled with what it means to work "for development," a concept entirely entangled with questions of impact (Dell & Kumar, 2016). Understanding the researcher's roles in these communities and how their inventions fit in socially, practically, and sustainably are imperatives for these researchers to think through. As one example, researchers have identified ways that technology can reinforce patriarchal social systems (Tanis & Postmes, 2005; Vashistha et al., 2019). Through a deep awareness of how to have actual impact, Sultana et al. recommended designing within the patriarchal system, despite wanting to subvert it (Tanis & Postmes, 2005). They go on by saying, "To be clear, we certainly might want to directly fight against the patriarchy. […] However, if we want to work within this community, we have to work within the situation as it is. It is not helpful or realistic to expect to change a deeply patriarchal society or for us as powerful outsiders to insist on some of its most subjugated members that they should want a different life. Instead we have to work within this system if we want to have a chance at creating some meaningful change" (Tanis & Postmes, 2005, p.9). Through this illustration, we can see how ICTD research has wrestled with recognizing its direct effects on their participants and how to sustainably have an impact. This understanding informed our own wariness of technological solutions and helped us to contextualize concerns researchers in this study shared about their own work and work by others.

3.2.7 Allyship

We initially approached this work with allyship, a common framework for countering marginalization, in mind. While many definitions exist, some scholars have defined allyship as defending and working toward the betterment of an oppressed group (Iyer & Leach, 2009; Brooks & Edwards, 2009). Across the literature, there are four common components to allyship: 1) the ally is a part of a dominant group working to help an oppressed one (Evans & Wall, 1991), 2) the ally has a privileged power as a result of belonging to the majority (Broido, 2010), 3) the ally challenges those within their own group(s) (Tatum, 1994), and 4) the ally participates in "political solidarity" in which they use their majority power to challenge authorities (Subašić et al., 2008). Some have criticized allyship and conceptions of being an ally for ignoring that people can hold multiple identities at once (Mizock & Page, 2016), reinforcing the social hierarchy by prioritizing the act of allyship over the groups they are trying to help (Russell, 2011), supporting a "hero-victim narrative" in which the ally acts as though they are saviors, and actually being "pseudo-allies" with ulterior motives (i.e., elevating their own social status (Evans et al., 2005) or expecting praise (Rodopoulos, 2004)). Large concerns of allyship center around saviorism and tokenization, in which people use others for their marginalized experiences (e.g., asking someone to collaborate solely because they speak a certain language and the project needs translation services) (Russell & Bohan, 2016; Laws, 1975). Russel identified different motivators for allies; they can be selfless, such as pursuing social justice, or self-serving, such as acting as an ally only to absolve their own guilt (Russell, 2011).

Across these concepts of intersectionality, reflexivity and positionality, membership, equity and justice, impact, and allyship, there are shared values of prioritizing the well-being of researchers and participants while also striking a careful balance between the two; however, doing so may only be possible in the most idealized sense. Researchers may find difficulty in navigating these various theories in practice. What does it mean to embody such beliefs in one's approach to research? In order to examine our research questions, we set out to document and analyze the lived experiences of current HCI researchers and how they manage such entangled and sometimes competing concerns.

3.3 Methods

3.3.1 Recruitment

We recruited researchers who considered themselves to be HCI researchers and who currently or have previously worked with marginalized people to participate in a survey and/or interview. We openly defined marginalized people as anyone who is oppressed by a system of power.

Our recruitment plan, using word-of-mouth and snowball sampling, was based on that of previous research examining experiences of HCI researchers (Smith et al., 2018). We began recruitment using social media, taking advantage of the vast networks from our own Twitter accounts. According to Twitter's analytics, our recruitment tweet reached 12,269 users, 222 people interacted with the tweet, and was retweeted 28 times. At the CHI 2019 conference in Glasgow, we approached researchers whose work we saw as meeting the above definition, and we distributed recruitment flyers at related CHI workshops and sessions (e.g., the Queer(ing) HCI: Moving Forward in Theory and Practice Special Interest Group (Spiel et al., 2019)). In our recruitment interactions, we also asked people to forward our study to researchers whose perspectives might help speak to HCI research with marginalized people. With this recruitment approach, we sought to include perspectives from researchers who self-identified—or were identified by others in the HCI community—as conducting research that engages with marginalized people. Recruitment lasted three months, from April to June 2019.

Based on participants who chose to disclose their identity in the survey or participate in the interviews, we know that researchers who responded to our calls represented primarily Western, and especially United States-based, perspectives. Despite our efforts to recruit broadly by reaching out to non-US based researchers directly, the majority of the participants in this study are US-based, and beyond that, based in the Global North. Most likely due to our own biases, focus of our professional networks, and language used in the recruiting call, we might have missed recruiting researchers based outside of the Global North. The language in our recruitment calls may also have contributed to this bias; for instance, there are cultural differences in how people understand the term "marginalized people." It is also important to note that our sample of participants, and thus our resulting themes, may not be broadly representative of the HCI community's views and values. Further, *any* recruitment of academic researchers is susceptible to "privilege hazard," defined by D'Ignazio and Klein as "the phenomenon that makes those who occupy the most privileged positions among us—those with good educations, respected credentials, and professional accolades—so poorly equipped to recognize instances of oppression in the world. [...] The privilege hazard occurs at the level of the individual—in the interpersonal domain of the matrix of domination—but it is much more harmful in aggregate because it reaches the hegemonic, disciplinary and structural domains as well" (D'Ignazio & Klein, 2020, p. 29). The small aggregation of ours and participants' experiences presented in this work risks reifying what is or is not oppression in ways that miss key instances of oppression, particularly when those instances have caused people to leave the field or not have the time or the security to volunteer for a study such as ours.

Because surveys allowed for anonymity and interviews provided more depth, we gave participants the option to take an online survey, participate in an interview, or both. Our university's Institutional Review Board determined this study to be exempt. Participants reviewed consent materials before the survey and interviews, and we provided interview participants with a $25 USD gift card as an appreciation for their time.

We estimated that the survey would take 15 minutes to complete. The survey asked participants to reflect on a previous, specific project of theirs and around publication practices such as providing a reflexive or position statement and any potential criticism or praise that resulted from the work. Further, the first author conducted semi-structured interviews either in-person or virtually. We also asked participants to reflect on a previous, specific project of theirs that worked with marginalized people, discussed allyship in research and more broadly, and had conversations around the research ethics involved in their work. Please see Appendices A and B for the full survey and interview protocols.

We used Dey's concept of theoretical sufficiency (Costanza-Chock, 2018) and Fusch and Ness's rich and thick metrics (Fusch & Ness, 2015) to determine when to stop data collection. As we moved forward in our analysis, the research team agreed that our data were both extensive and contained rich, complex discourse, and we decided that we had built enough understanding to construct a theoretical contribution. However, we recognize the possibility of further theme development beyond this stopping point as a limitation (Braun & Clarke, 2019).

To try to minimize power dynamics with interview participants, the first author, a first year PhD student at the time, conducted all interviews alone; however, we still could not completely detach ourselves from the influences of power, especially with the more senior researchers connected to the study. We took additional steps to make it easier for people to participate without judgement from the senior researchers on our team or the greater community. First, we made it difficult to link surveys with specific people by allowing for anonymity and not linking survey responses to potentially identifiable information about demographics, information about membership, or groups studied. We also integrated member checking into our analysis process to validate our understanding of participant responses with participants, documented in Section 3.3.3.

3.3.2 Participants

A total of 24 participants participated in this study: 10 only took the survey, 5 only did an interview, and 9 participated in both. Interviews ranged from 55 to 92 minutes (mean: 65 minutes), after which they were fully transcribed. Of our interview participants, 1 self-reported that they had been in their field 1-2 years, 11 for 3-6 years, 6 for 7-10 years, and 6 for 10+ years. Table 2 shows a further breakdown of our survey and interview participants, presented in aggregate to preserve anonymity.

Do you consider yourself as someone with one or more marginalized identities?	14 yes; 3 no; 2 prefer not to say
Represented fields	HCI (n=17), CSCW (n=14), STS (n=4), Education, Public Health, Disability Studies, ICTD, Communications, Psychology, and Design Studies *only list n when >= 3
Primary methods	Qualitative (n=10), Quantitative (n=3), Ethnography (n=4), Design Research (n=3), Mixed Methods, Implementation Science, Policy Research, Political Economy, Critical Theory, Infrastructure Studies, Contextual Inquiry, Participatory Design, Computational *only list n when >= 3

Keywords	Assistive technology, games, disability, marginalized communities, queer, social computing, CSCW, marginality, wellbeing, ethics, social media, health, software, collaborative teams, community formation, usability, privacy, implementation science, disparity reduction, rural, participatory design, innovation, work studies, social innovation, marginalized communities, accessibility, design, disability studies, children, play, inclusion, neurodiversity, child-computer interaction, HCI, ICTD, Global South, voice, inclusion, political economy, accessibility, social computing, economic development

Table 2. Self-reported demographic follow-up table

3.3.3 Analysis

Through Braun and Clarke's reflexive thematic analysis approach, we used a mix of inductive and critical realist frameworks to guide our analysis (Braun & Clarke, 2019). Using such frameworks allowed the research team to derive meaning from the data and to reflect on the data from both localized and broader perspectives, valuing lived experiences and situating them in their socially constructed contexts. Additionally, reflexive thematic analysis calls for researchers to reflect upon their own assumptions. In this work, we initially set out to understand the relationship between HCI research and allyship, as we saw this as a valuable framework to analyze such a topic. We were surprised to find that allyship is just one dimension in thinking through research that involves marginalized people, and our generated themes reflect a wider array of considerations.

To familiarize ourselves with the data, the three authors reviewed survey responses and transcripts of interviews. Next, the three authors applied a modified open coding approach to analyze the data. Authors reviewed half of the interview transcripts and survey responses, identifying quotes relevant to our research questions, grouping them, and describing groupings with short phrases. We conducted this grouping and coding activity concurrently, contesting and discussing each other's interpretations of the data. Following this, the first author coded all interview and survey data while consulting with the rest of the research team, building upon our initial groupings to construct themes. We then organized the themes according to our research questions about the kinds of interactions and people involved in research (researcher, participant, HCI as a whole, see Table 3), and we present the themes accordingly. While we present themes from both survey and interview results, we illustrate them with quotes from the interviews, as the interviews were richer and more illustrative than the survey responses.

Finally, we reached out to interview participants to member-check themes and data presented. We first presented participants with their quotes and our analysis to validate our interpretation of their data. Participants were given the option to omit entire quotes or any specific details that they felt were more revealing than they were comfortable, but they could not otherwise edit the content of quotes (Lee & Hume-Pratuch, 2013). We made changes to quotes and built upon or clarified analyses with their direction, and all but one interview participant completed the member check. We reached out to participants a second time for more demographic information to provide Table 2. Last, to recognize the work behind the perspectives that participants shared with us, we gave participants the option of being identified with their quotes and examples. After data collection ended, 5 participants were interested in identification in the publication. After a final round of member checking with these participants, 3 still wished to be identified. Similar to previous meta-HCI studies (Smith et al., 2018), the close-knit nature of our community presents a challenge in protecting anonymity. To address this, we do not present personally identifiable demographic information.

3.4 Findings

Responses from our surveys and interviews introduced tensions for different relationships in research: *researcher to participant* and *researcher to researcher*. When discussing the latter, participants also surfaced how HCI as a field played a larger role in influencing these dynamics, identifying a third, higher-level relationship in research, *HCI to researchers to participant*. For each, we describe resulting harms and, when applicable, considerations that participants make to address them; however, we did not find a one-to-one relationship between the two. Please see Table 3 for a full breakdown of our themes. Additionally, we refer to participants of this study as HCI Researchers (HCIR) to better differentiate them from participants who took part in the HCI researchers' studies.

	Resulting Harms	**Mitigating Harms**
Researcher to Participant	Participant costs of doing research Encountering "empty" allyship	Acknowledging limitations as a researcher Shared membership with participants Taking steps to reduce exploitation through personal work, compensation, maintaining relationships, member checking, and study accommodations
Researcher to Researcher	Tokenization and asking invisible labor of researchers with marginalized identities Tensions of reflexivity and positionality among researchers Effects of membership on marginalized researchers and how their work is perceived	Critical reflections when asking for labor Balancing harms and benefits of reflexivity and positionality statements
HCI to Researcher to Participant	Technological solutionism and expectations	

	Impacts on marginalized researchers in HCI	

Table 3. Constructed themes grouped by interactional relationships

3.4.1 Researcher to Participant

To address the first research question—how HCI researchers engage in and reflect on research with marginalized people as it affects participants (from researchers’ perspectives)—we examine responses that illustrate harms that can result from this interaction and considerations to account for them.

3.4.1.1 Resulting harms of the researcher to participant relationship

The HCI researchers who participated in our study emphasized two ways their work affects participants of marginalized backgrounds: the unequal give and take when people participate in research and how allyship can extend towards participant identities and experiences.

Participant costs of doing research

The 24 HCI researchers characterized their work to extract data from participants in their studies as exploitative, because their work requires learning about marginalized people’s experiences and perspective. The guilt of giving little back to participants was a shared sentiment among the researchers in our study. HCI researchers experience considerable professional benefit from this work but feel they are returning fewer benefits to the participants in their studies. HCIR20 recognized the unbalanced giving and taking of doing research with marginalized people: “*there is so much you're learning from them, which you are putting out, but the knowledge which you have inherited, the papers you're writing, the awards and fellowships you are receiving. There are a lot of things which you are taking from them, including their time,* *including their resources. And we are giving very little to them."* While it is important to acknowledge what researchers are taking from participants of their studies, it is possible that participants do not perceive this to the extent a researcher might fear. To answer such questions, researchers might develop ways to check in with the people with whom they are working about whether and what they are getting from participation. Through this, researchers might better understand how participants are experiencing their engagement in the research: sometimes this might lead researchers to change their practices, and at other times, it might reduce their guilt.

In the United States and many other regions, a human subjects review process is nominally charged with examining benefits relative to risks. However, the ways an institutional review board conceives of risks and benefits may not align with participant experiences and is mostly prospective: other than reporting of adverse events, there is no during study or post-study assessment of how participants experienced the risks and benefits. Participants in our study noted deficiencies with this process. In thinking about risks, HCIR15[4] called for the "*need to think more about this violence as it's defined by social justice groups.*" As they pointed out, harm from a study can be more than what we traditionally conceptualize as risky (i.e., physical harm), and so there is a need to reframe the definition of risk to account for microaggressions and actions that further marginalize others. HCIR16 discussed how unbalanced costs and benefits contribute to the marginalization of the people with whom we work: "*too many times, folks do the research, they leave, they don't say anything and never come back. And then these marginalized folks have been used, further marginalized by folks writing about marginalization.*"

---

[4] Cynthia L. Bennett's research sits at the intersection of Human-Computer Interaction, accessibility, and Disability Studies. Her work spans from the critique and development of HCI theory and methods to designing emergent accessible interactions with technology.

Encountering “empty” allyship

The HCI researchers in our study emphasized the need to go beyond performative allyship to more meaningful forms of allyship. They offered definitions of this more meaningful allyship, as some emphasized that allyship should involve leveraging one’s privilege to “*further the cause together*” (HCIR2). HCIR6 discussed how allyship cannot be self-serving, while HCIR8 explained that allyship is not something you can “*step in and out of.*” HCIR14 additionally talked about the importance of taking risks in allyship, emphasizing that there needs to be something at stake for actions to be effective.

The HCI researchers in our study also noted that current allyship practices in the HCI community often falls short of these ideals. Some questioned whom allyship actually serves. HCIR5[5] described that “*it's become a word that anybody can attach themselves to.*” HCIR8 talked about his stance on “empty” allyship: “*I think people distrust that term [ally] now because the people who purposely adopt the term ally then don't do the work. [...] when it comes down to it, even when it comes down to a conflict that they're having with someone in their personal lives, they actually don't step up and defend that community in any way.*” HCIR15 underscored an important distinction in defining allyship: “*I think the biggest thing is process, not product; ongoing versus achievement. It's hard because when we do things like allyship trainings or buttons, the good that it does should also be held with the [harmful] message that it sends, that it's an achievable task*.” Additionally, HCIR16 raised a concern that gets at the heart of empty allyship: “*allyship is another way of centering folks who aren't impacted, to make them feel*

---

[5] Jean Hardy is an ethnographer who uses community-based participatory research methods, including participatory design, to better understand the technological needs and futures of rural LGBTQ communities.

included when they're already included." These accounts of the potential failings of allyship efforts highlight both dangers of such actions and opportunities for improvement.

3.4.1.2 Mitigating harms of the researcher to participant relationship

The 24 HCI researchers shared how they work to avoid and mitigate harms that participants experience as a result of involvement in research. This includes personal work as a researcher as well as care in research design and execution.

Acknowledging limitations as a researcher

Many of the 24 HCI researchers described the limits on what they can accomplish with a sense of guilt and frustration. HCIR20 explained that "*you are going to make mistakes. And the question is that you don't make massive blunders, but you make whatever the mistakes you're making can easily be corrected.*" As many of 24 HCI researchers emphasized, researchers should not let this acknowledgement of their limitations stop them from doing vital work. HCIR14 described the importance of knowing that they might make mistakes: "*I couldn't let this fear and worry and guilt stop me because this is what's important to me. think too in a lot of these conversations is, and when we're ready, we have to do it. We just have to do it and put ourselves out there and try it and be willing to recognize that you're wrong and ask if you're wrong.*" HCIR16 also talked about the importance of embracing the associated discomfort as a way of managing the guilt, concern, and frustration that might result from noting these limitations: "*if you're feeling uncomfortable in this sort of instance, don't hide that. Don't try to solve that. You're not going to solve that discomfort, because that discomfort is structural.*" HCIR16 encourages us to ask what and how structural forces cause researchers to feel badly and to then accept those feelings as part of the research process.

What about the way HCI research is done makes some mistakes acceptable and others not? Do we agree with that evaluation? Harm can result when individuals and the field accept that some avoidable harms are unavoidable. Harm can also result when the guilt about the imperfection of any research process prevents someone from doing good work or causes them to carry so much guilt that it affects their own wellbeing. How do researchers know—as HCIR14 describes—when they are "*ready*" and "*just have to do it*" and when they are not? Having better ways to reason about how to assess one's own limitations and whether and how they should proceed with research could lead to research that does less harm—to both participants and to researchers who otherwise carry guilt or shame about their work.

Shared membership with participants

A common theme throughout our data centered around how membership—having shared identity or identities with participants—affected how the HCI researchers in our study thought about their work.

Several participants discussed their non-membership, in which they did not feel that they shared identities with the people they chose to study. For some, non-membership was a source of questioning of whether they were the right person to do the work and/or whether their analyses accurately captured the voices of those they worked with. Others expressed that non-membership should not limit involvement in work that involves marginalized people. To this end, HCIR8 explained that there are several things researchers with no shared identity can do, including being open to learning from others: *"I don't really believe that you have to be a part of a group to do valuable and beneficial and not harmful research on that group. It's just an amount of A, trying to educate yourself beforehand and to really learn about those things and challenge your own assumptions about it and then B, to accept criticism if it doesn't go well."* HCIR2 discussed how they grappled with taking up space within the research community as a non-member: "*if* *there aren't white allies doing the work and trying to do it with an equitable framework and it is just everybody only focuses on their own groups, then that can really continue to perpetuate ignoring populations, and I would rather be doing the work and trying to do it better than not do it at all*." HCIR2 lays out what might happen if allied researchers only work with groups with which they feel membership, explaining how HCI research might continue to ignore specific marginalized groups. They also present a question worth considering: is it better to conduct HCI research with marginalized people, with potential for harm or positive impact, or to not do it at all? One way of thinking through this concern is to compare the potential for harm from carrying out the research or not doing it. At the same time, this sense of "*white allies*" needing to do the research—or no one else will—should also remind the HCI community of the urgent need to dismantle barriers to participation in our community that result from a long legacy of racism, sexism, ableism, and many more forms of oppression.

Some of the 24 HCI researchers also had shared identity with the participants they worked with, and they talked about how they experienced this as both an advantage and a limitation. HCIR5 explained how shared identity had benefited them: "*My position as an LGBT person and somebody who has lived in rural communities allows me to identify with the people that I'm doing my research with and build bonds with them. That makes the research that allows for more depth more quickly*." They also recognized how this shared identity still did not mean they could speak for or relate to the experiences of everyone with that identity. As HCIR5 summarized, *"I am thinking a lot about what other people's experiences of similar identities and geographies are to me and how they're different from mine. [...] I'm drawing from my own experiences, but then I'm also constructing my subject position in a way that understands that my experiences aren't everybody's experiences."* HCIR16 reiterated this: "*maybe someone in the exact same sort of constellation of identities has a complete different experience. Both could be marginalizing, but* *both might see and experience marginalization in different ways and the ways in which possible solutions emerge could be different.*" They underscored that researchers who have membership with their participants should still be "*frank with the limitations of [their] perspective.*" When researchers consider their identities through an intersectional lens in this way, they may better understand, mitigate, and communicate the limits of their research approach and claims.

Taking steps to reduce exploitation through personal work, compensation, maintaining relationships, member checking, and study accommodations

As noted earlier, the HCI researchers in our study described grappling with what they experienced as an uneven exchange between researcher and participant. They also described the steps they take to make that exchange more balanced and less exploitative.

One of the most common recommendations they made for scholars working with marginalized people was to learn and draw upon previous research, especially when it can be done in place of asking marginalized people. This can lessen what researchers ask of marginalized people in educating others—an often invisible and unrewarded form of labor—and also elevate scholars who are already doing this important work. Others talked about the value in doing "*personal work*" (HCIR9) in preparation as in working through personal biases. Additionally, HCI researchers have worked to lessen the burden of what scholars ask of participants and rebalance what participants receive in return. HCIR8 asked himself, "*what is the work that they've already done? What are they constantly asked to do anyway that then doing an interview with me is just going to make this more painful?*" HCIR14 shared how it is the researcher's responsibility to protect their participants, such as by anticipating how their work might have unintended consequences: "*where could this go wrong? I can't let myself get overwhelmed by that, I realized, because it is my responsibility and I have to do the participants justice by making sure that I think* *about the possible ways this research could be misappropriated or misquoted. I have to put in that time and I will and I do. But then there's also some things that are out of my reach and I just did not think about that possibility.*" Here, HCIR14 emphasizes how listening to their doubts pushes them to do the research as well as they can, while also needing to accept that the research may not ever be perfect so they can move ahead. This does not resolve, however, when to move forward or not.

The HCI researchers we heard from pointed to several, specific ways they reduce exploitation: expanding definitions of compensation, maintaining relationships with participants after a study, teaming up with community partners, member-checking data, and making participants feel comfortable in studies, described in further detail below.

Many of the 24 HCI researchers talked about the importance of compensating participants fairly. Recognizing the experiences of their participants—expensive health conditions or greater difficulty finding employment, for instance—researchers strongly prioritized payment. HCIR15 considered how appropriate payment is crucial, yet under-practiced, and valued giving back beyond or in addition to the monetary, traditional approach to compensation. For instance, HCIR14 suggested providing a job reference after long-term study engagement.

Some HCI researchers in our study talked about how they approach their relationships with study participants, past and present. HCIR7[6] pushed for researchers to "*be transparent and be open about your intentions and maintain contact*" and added, "*don't disappear on them*." P6 expressed: "*I'm not just going to like suck all this out of you and disappear.*" Many researchers

---

[6] Kate Ringland is a critical disability scholar who studies how games and play support sociality.

shared this concern about abrupt exits after studies and how that would affect participants. Transferring research systems to community partners, for ongoing support and development, was one technique participants suggest for better managing the end of studies.

Many of the 24 HCI researchers discussed their experiences working with community partners more broadly. HCIR5 explained that "if you want to generate novel insights, you really need to be either embedded in those communities or you need to be very intentionally partnering with people in those communities." HCIR16 recommended that researchers not "invent the needs of the community, [...] but go to the people who are doing the work and ask, 'what can I do?'" Partnership also enhances work, as HCIR5 stated that they "believe personally and ethically that the best kind of research that is done with marginalized people involves those people explicitly in some form or fashion."

Member checking helps assure both readers and authors that they are accurately interpreting their participants' experiences. HCIR9 described that they "*hear about whether they [the participants] think we've got it right or not.*" HCIR18 also brought up that member checking helps participants feel comfortable with the work that researchers are putting out. HCIR5 acknowledged that member checking requires additional organizational labor (e.g., keeping track of people and their contact information) and labor for participants but also stated "*it usually makes my research stronger because then when I start talking about the themes of the research and how I interpreted what people were saying, they are like, wow I didn't think of it that way. And all of a sudden, we can have an additional conversation about the findings and I can gather even more insight from them. So I actually treat member checking as secondary data collection.*"

The 24 HCI researchers discussed how they thought about making participants comfortable in their studies. They mentioned several examples of this including letting participants choose the location of where to meet, avoiding language that participants expressed discomfort over, and allowing participants to take breaks on their own time. Several participants mentioned that they thought about ways participating in the study might burden participants, so they sought to accommodate them by providing food, transportation to and from the study, and accommodating accessibility needs. As HCIR15 stated, "*space is just so political, and hard to get right.*"

As the HCI researchers in this study laid out what they have done to address exploitation in their research, they also discussed that doing so can be difficult and take extra work to have a meaningful impact while doing as little harm as possible. However, they underscored the importance of making this effort.

3.4.2 Researcher to Researcher

HCI researchers in this study with marginalized backgrounds experienced strained relationships with other researchers, and some described ways they navigate these tensions, while also noting ways other researchers could reduce them.

3.4.2.1 Harms resulting from the researcher to researcher relationship

Tokenization and asking for invisible labor of researchers with marginalized identities

For the HCI researchers in our study with marginalized identities, an invitation or request to participate in a research project engaging people with shared identities could be simultaneously welcome and a cause for concern. Were they being asked to participate for their expertise as scholars, who also bring added perspectives from of their identity? Or tokenized, regarded as a necessary box to check to be able to do the research?

HCIR8 reflected on how difficult it can be to discern colleagues' true motives for including him in a project, noted, "*at some level though, you kind of want to be tokenized, which is weird.*" This was a shared sentiment among other marginalized HCI researchers in this study: being tokenized by other researchers can be disrespectful and exploitative, but it is also sometimes a starting point to meaningful engagement and better research. For an HCI researcher with a marginalized identity, declining to participate in such a study may leave them wondering if the other researchers will make mistakes and cause harms that could have been avoided if they had contributed. Consequently, many join out of a sense of responsibility: "*so often I feel like if I don't do this, somebody is going to mess it up*" (HCIR15). In this way, many people with marginalized identities in the HCI community take on additional—and often unrecognized—labor to further equity and justice in specific projects.

Other researchers from our study shared their experience being on the other side of a request as they sought to involve collaborators who had shared experiences with their study participants. HCIR13 explained their reasons for doing so: they "*really tried to not just involve community members in the research process, but also engage with other researchers who are also sharing this identity.*" HCIR8 laid out the tension of wanting to check his work was not going to be harmful and not wanting to ask for too much invisible labor, while also rightly pointing out that there are institutional reasons involved:

> *I like to get input on the kinds of questions I'm asking or the approach I'm taking with other people in the research community who might either identify with the group that I'm conducting research with, but also might just work also heavily with that group. But I think there are limitations. On one hand there are limitations where I don't want to bombard specific researchers who are already a minority in our community with more labor, for*

> *having to answer questions about their own identity all the time. And then on the other hand, there's the fact that I might not have connections with those people in our community or there might not be those people. For example, I don't think I know anyone who's a trans black woman in HCI. And that just speaks to the fact that our community is not as diverse as it could be. Then on top of that, if there was one person, I wouldn't want to be that person who's just reaching out to ask for effort. So I think there are kind of barriers to that approach. But, ideally I would want to make sure that I'm not acting as if I'm the expert on someone else's identity.*

Tensions of reflexivity and positionality among researchers

The HCIR researchers in our study contested the appropriateness of asking for reflexive statements, finding value but also potential harms in them. Focusing on the potential benefits, HCIR15 described that they "*would love reflexive statements if they do the work that needs to be done, which is saying we, by having these connections, were suited to work in this space*." They want on to say that reflexive statements also help researchers with "*being really clear about the lenses [they are] using.*"

Despite these benefits, many of the 24 HCI researchers pushed back against suggestions that reflexive statements should be a norm. Some expressed that requests for these statements can be akin to asking researchers to disclose their identity to the research community, and that this can disproportionately and negatively affect researchers who experience marginalization. HCIR8 shared his own approach to disclosure and reflexivity:

> *There's a level of danger to constantly self-disclosing. This is actually something that I purposely generally choose not to do in my research. I will self-disclose to my participants when I'm recruiting them and talking to them. But I will not do so in papers because I just*

> *have a level of paranoia that might be tied to all of the background research that I read, the literature reviews I've done about how, for example, documenting identity in classification systems can lead to really bad things if you live in a country where your government suddenly changes and directly attacks those people. So I think that self-disclosure as an expectation is something that we shouldn't be doing and I would encourage other marginalized researchers to push back a little bit if they feel like they should. They're forced to do that because it can be dangerous. And it could lead to professional harm, because there are people in our community who have biases and maybe we just don't know about them.*

HCI researchers in this study cited reasons for not wanting to disclose their identities in their work, such as HCIR13 saying "*I didn't want to out myself in print forever.*" HCIR8 explained that the current dialogue "*is limited in perspective and embraces this universality of experiences, that disclosing that you are a woman or disclosing that you are white is much different than disclosing that you are a trans person or a trans woman or disclosing that you are black. The types of retaliation you might face for doing that are much different.*'' HCIR13 explained how the current ways in which the HCI community asks for reflexivity "*assume that the person is not a member of the group*" and how this is "*really dangerous, especially when the implications of disclosing can be much more severe for marginalized people than for others.*" As HCIR15 put it, "*it should be my choice*" whether to disclose or not, and HCI should be conscious of the power dynamics involved in asking for reflexivity. They explained that a culture of reflexivity can also do more harm to researchers with marginalized identities, as the pressure to disclose one's identity or identities may take away from their agency. They also noted that, while getting work published or progressing in one's career is usually not contingent upon including reflexive statements, researchers should be aware of the ways that setting this expectation could end up outing marginalized people.

Effects of membership on marginalized researchers and how their work is perceived

There were different perspectives on how membership can both add to and take away from the research process and how other researchers perceive the published work. For instance, HCI researchers we heard from discussed how their shared identity benefited their work (e.g., providing a source of confidence in carrying out the work). While membership can provide many benefits to work that involves marginalized people, some of the 24 HCI researchers pointed out the ways that membership does not and cannot solve everything. HCIR5 pointed out, *"I will also say that I don't think that having an LGBTQ person on your research team [...] I don't think that's a fail-safe. So that doesn't mean that you are guaranteed your research isn't going to be [messed] up. You could still do [messed] up research [with queer people] as a queer person."* HCIR15 talked about how their identity gave them more authority in the research community, but only so long as they worked in areas related to their identity:

> *Unfortunately, people with disabilities doing disability things is a little bit more palatable than people with disabilities doing not disability things. I also knew that I have a platform where I get to say things because I'm disabled and so I have chosen to use that. But in other ways, I'm also putting forward a very white and cis and straight and also academic part of that. I know that that is wrong and it's harmful to the people who are producing knowledge that I could not live without but has become integral to my existence.*

HCIR15 also noted that this added authority is not always a positive: "*I do need to question just because someone is disabled, doesn't mean that they're doing good work, right? [...] So people are going to read that some researchers are disabled in my paper and you're probably not going to question the work in the same way. And I don't think that that's fair. I think that maybe I'd* *appreciate if they didn't question statements like 'people with disabilities are disadvantaged,' but I think that it's very, very important that people do question the work."* HCIR15's stance captures the careful balance of giving authority based on membership.

HCIR5 echoed this tension around perceptions of who can (or should) do research with marginalized people. "You don't want people doing the research that are going to do it in a way that's disrespectful or don't understand [what is] actually happening. But at the same time, pigeon-holing all [marginalized] people into doing [marginalized] research is also not the answer. So in that way, it gets a lot more complicated because if somebody showed up to a conference [and were not a part of the marginalized people they were presenting on], I might question their expertise on the issue. So that's one thing that I'm struggling with. I don't necessarily know how we don't place the burden on the people that are already burdened." Here, HCIR5 identified a tension of gatekeeping based who does what research based on membership or identity. If anyone can work with marginalized people, then they may be more likely to do the work poorly. If only marginalized people can do research within their own groups, then they must carry the burden of pushing knowledge contributions themselves.

HCIR15 also emphasized overall cultural issues of academia. HCIR15's research builds from scholars who are queer, trans, disabled, Black, indigenous, and/or people of color, whose contributions are too often under-recognized and exploited. Unfortunately, discrimination and hostility from other academics have pushed many of these researchers out of their fields despite their production of crucial knowledge.

3.4.2.2 Mitigating harms from the researcher to researcher relationship

Despite the challenge of navigating harms created by other researchers, the HCI researchers in this study suggested some techniques for reducing them.

Critical reflections when asking for labor

HCIR14 offered a set of questions for researchers who wish to seek out collaborators because of their experiences as a marginalized person: 1) why am I asking *this* specific person? 2) what am I asking them to do? 3a) am I asking them because it is the easiest option? 3b) could I ask someone else or look it up? 4) is what I am asking them to do appropriate, and further, appropriate for myself or them? 5) how am I going to compensate them? Is the request reciprocal? HCIR14 noted that it is important for faculty, primary investigators, or the person with the most power to actively consider these questions. They emphasized that the responsibility to account for these questions should not fall solely on junior researchers.

Balancing harms and benefits of reflexivity and positionality statements

HCI researchers in this study discussed how self-disclosure can either bolster their work or detract from it. HCIR8 outlines the tension:

> *There's a level of encouraging self-disclosure because it can actually encourage further trust in the research. So you say from my perspective, I am, for example, maybe I'm a queer woman, so [...] I bring these new perspectives to this research that are really beneficial. But then there's also the problem where not everyone reading that paper actually thinks that's a benefit [...] there is that potential again of people who are just biased and then they immediately think this paper is garbage because they think the researchers are too close to the problem, which historically super positivist research has always been like that.*

Neither authors nor reviewers can always anticipate the outcomes of disclosure; they can be positive and/or negative, beneficial and/or detrimental. HCIR15 added to this idea by describing how they sometimes reacted to disclosure: "*when I read papers and on the rare occasion, someone discloses that they are a part of this group, I do tend to take it more seriously.*"

Requiring reflexivity and positionality may also contribute to gatekeeping of research that involves marginalized people. HCIR20 explained that with an expectation to disclose one's identity, "*there are preconceived notions about who could do certain kinds of research.*" HCIR16 talked about how "*there's also then a pressure of 'do we have to all out ourselves at the beginning of every paper in order to justify writing about something?'*" HCIR19 echoed this by saying that they "*don't think someone who does research in [...] anything that deals with anything marginalization-related has to feel like they have to disclose that about themselves for their work to be legitimate, to be perceived as legitimate.*" HCIR13, however, points out that perhaps this gatekeeping device might be beneficial especially for researchers with non-membership: "*I do like to see that people who are not part of the population they are studying are reflective and thinking about their position.*" HCIR13 went on to note, though that using membership as a guideline for when to ask about reflexivity also requires making too many assumptions: "*It's really hard and I think about this a lot, the ingroup versus outgroup, what is and is not okay to ask. Because if it's someone who is cisgender, I do feel like we have the right to ask them why [they study trans populations]. But then you can never assume that someone's cisgender, you just can't.*"

Across these experiences and reactions, the researchers in this study noted the potential of positionality and reflexivity statements to support both researchers and their audience in understanding the perspectives, strengths, and limitations of the work. At the same time, careless requests for such statements or using them in absolutist ways that control who can and cannot do the work can cause some of the very same harms that those who request them are hoping to mitigate. We return to constructive approaches reflexivity and positionality in the discussion.

3.4.3 How expectations from the field of HCI affect researchers

The HCI researchers in our study described a cascade of influence: norms and incentives in the HCI field affect how researchers treat both themselves and other researchers, and this then influences how those researchers interact with participants in their research.

Technological solutionism and expectations.

HCI research, in its pursuit of novelty and innovation, can sometimes miss how the solutions that we put forth might actually affect the people we are hoping to help. HCIR9 discussed how "*a lot of HCI things that I see don't necessarily get into broad availability. They're more kind of investigative, so some things might not be quite as important or come up as often because things are earlier in the development cycle, but I think we need to systematically think about it.*"

Also in this drive to push forward, the HCI field can create a falsely positive narrative around research: that it is a clean, straightforward process when it is actually a messy one. HCIR20 explained that "*as a field, we are also motivated or could talk about positive things, not as much as the negative things or the negative experiences. And there is a lot of value in doing so as well.*" Involved with this is the pressure to produce work and do so quickly. HCIR20 went on to explain: "*we are also in one way or the other are incentivized to write quickly, do work quickly talk about positives*" and that this makes it more difficult to "*find the right literature, find the right best practices, to find the negative experiences*" which are "*really important for a new person who's coming and joining in the field and trying to change the world.*"

Additionally, HCI researchers we heard from described how other researchers should be mindful of what solutions we push forth. As HCIR16 explained we as researchers "*shouldn't be the people driving the solution, it's about how it is that we drive conversations around possible solutions.*" HCIR20 called for researchers to not get overly optimistic with the power of a technological solution. While they can have great impact, it is rare for these solutions to lead to revolutionary change. They went on to recommend that researchers "*recognize that this is just incredibly complex space where technology is a very, very small piece and where exactly it's going to fit and how well it's going to work.*" Finally, HCIR20 talked about how researchers should think about how technology fits in systematically:

> *There is a lot of enthusiasm about technology and when new people who are coming into the research with a technology background or wanting to use technology for societal work, that gets [...] really enthusiastic about how technology can change the world. [...] Only with experience, you really feel that technology is not going to be the main player.*

In other words, HCI researchers should not overestimate their work's impact and must remember that technology is just one component for systemic change. For all HCI researchers, understanding and communicating the limits of technological interventions is a crucial part of doing the research. For those who want to be allies, that understanding is also crucial for knowing when technology is or is not the appropriate solution.

Impacts on marginalized researchers in HCI.

The 24 HCI researchers talked about improving the publication review process by not asking for author disclosure. As they suggested, reviewers should recognize that their power, especially over junior researchers who are increasingly pressured to publish, can have great consequences. HCIR13 reflected on an experience in which they felt pressured to choose between disclosing parts of their identity and publicly outing themselves:

> *At the time I really needed to publish, really wanted to publish. I feel when you're very junior, there's this pressure to get things published. And so if the reviewers at that point had told me, yes, you need to do this [including a reflexive statement], I would have done it and I*

> *would have regretted that. So it's really kind of dangerous because I think there's a lot of reviewers nowadays who are pushing people to include these [reflexive] statements.*

Further, HCIR8 outlined a burden that other researchers place on researchers who experience marginalization:

> *I feel like there's an expectation of justification put on research with marginalized communities that's not put on more general populations. What I mean by that is being constantly asked to define, for example, what transgender is in your introductions [...]. I get wanting to inform the reader, but at some level, when we're talking about people who exist in the world, there should be an expectation that researchers can inform themselves about that without the researcher to constantly redefine the same terms over and over again because not enough people actually research this community. Then on the other hand, there's constantly justifying why you chose to research with this community, which I feel in some ways re-marginalizes that community.*

These different accounts of experiences around disclosure highlight what is potentially at stake for researchers. For researchers who experience marginalization, there are additional, unfair pressures to continually out, define, and defend themselves to the HCI community. Here, we see opportunities for the field to develop guidelines for HCI authors about how to describe their positionality and for reviewers about how and when to ask for reflexivity. Recent efforts like the community-sourced guide for CHI 2021 reviewing are important steps toward this for the field (Kumar & Bardzell, 2020).

3.5 Discussion — Embracing Tensions

For the two interactions, *researcher to participant* and *researcher to researcher*, our findings reveal potential harms and how the 24 HCI researchers we heard from have addressed them. The *HCI to researcher to participant* relationship additionally uncovers the structural influences of HCI's norms and expectations and how they influence such harms. In the following section, we discuss four tensions salient across these interactions—exploitation, membership, disclosure, and allyship.

These four tensions are complex; even if researchers take all the precautions they can, follow any prescribed best practices, and make an honest effort to not make any mistakes, they still may not be able to resolve each tension. Resolution, however, is not the point, and to borrow an expression from HCIR5, there are no "fail-safes" in this line of work. As HCI researchers, we must come to terms with the possible harms that are tied to doing research, especially with marginalized people, and ready ourselves so that we are still able to make progress, minimize the potential for those harms, and have plans in place if they do occur.

It is also likely that researchers will experience each tension and how the tensions relate to one another in different ways. Drawing from Morgan's axes of oppression, a person can be placed somewhere along each axis, reflecting how much privilege and/or oppression they experience from that axis category (Morgan, 1996). So, researchers who face similar oppression along the same axis as their participants will have to confront a different set of questions and challenges compared to a researcher who has privilege on the same study-specific axis. This understanding of axis-specific marginalization compared to the people with whom a researcher works is key to avoiding a binary categorization in which a researcher is considered marginalized or not marginalized. In the following sections, we outline how each tension has competing, yet entangled priorities and then discuss what can and should be done about them.

3.5.1 The Tension of Exploitation

Participants in our study talked about exploitation on two broader levels: extracting experiences from participants and tokenizing the identities of fellow researchers. These forms of exploitation are complex to work through as both place unfair burdens on participants and researchers but are seemingly unavoidable in the current research paradigm. The HCI researchers in this study reflected upon how researchers treat participants, as many felt that they offer little back to participants compared to what they receive. They also flagged a tension at the researcher level, where it is unethical to involve researchers solely for their marginalized experiences, while some marginalized researchers spoke of being left with no other choice but to be tokenized to ensure that work is done with care.

Previous scholars have also emphasized the need for more equitable engagement with participants. In 2010, Irani et al. laid out “postcolonial computing” that rethinks practices of engagement in computing research (Irani et al., 2010). In this framework, the authors articulate an alternate research paradigm that acknowledges the power dynamics involved in research and views researchers and participants as equal partners in the knowledge-building process. Our findings extend Irani et al.’s call for a paradigm shift of exploitative research practices by identifying specific actions that researchers should consider. While these actions are certainly not enough to completely shift toward an equal give and take, they may provide short-term reprieve from an inherently exploitative process.

Participants in our study made several recommendations to better support those who participate in HCI research, which we summarize and discuss further below. First, working with community partners may prevent researchers from furthering their own agendas ahead of those of their participants. These partnerships work to balance the interests of researchers and participants alike. Next, getting involved in research should not come at a cost to the participant, and so researchers need to make appropriate accommodations such as access needs, transportation to and from the study site, and proper compensation. Researchers should also expand their definition of compensation and what they are actually giving back to their participants. Previous literature points out that is not as simple as paying participants as much money as possible; doing so might incentivize participants to take significant risks for more compensation (Williams & Walter, 2015). However, another study has shown that low-income individuals will ask for more payment if they feel that their compensation is unfair (Walter et al., 2013). Considering these points, we suggest that researchers pay more when participants ask for more compensation and search for ways in addition to monetary compensation that could benefit participants (e.g., learning how to design and create prototypes, recommendation letters, making connections to others they would not have met otherwise). Research can provide better ways to give back to participants more directly in the short-term in addition to longer-term benefits. Finally, researchers need to think about both the effects of their presence at a site and the short and long-term effects of leaving that research site once the study is complete, which directly aligns with principles in action research (Hayes, 2011). Taking time at the recruitment stage and the beginning of the study to explain what will happen when the study ends may reduce or prevent future discomfort (e.g., Will researchers take any interventions with them as they exit? Will they try to transition them to community partners if desired?). Last, individual-level reflection may also clarify whose priorities are being promoted, the researchers' or the participants'. In addition to the researchers of this study's call to do so, scholars of decolonial studies and indigenous studies provide further guidance for self-reflexivity (Smith, 2012). In *Decolonizing Methodologies*, Smith poses the following questions to researchers to self-reflect: “Whose research is it? Who owns it? Whose interests does it serve? Who will benefit from it? Who has designed its questions and framed its scope? Who will carry it out? Who will write it up? How will its results be disseminated?” (Smith, 2012, p. 10). Research teams might think through and discuss their responses to these questions at the beginning, throughout, and end of a study.

In addition to considering how we compensate and engage with participants, we must also continue to evolve how HCI as an interventional field evaluates ethics and risk. With recent criticisms of the Institutional Review Board in the US and a push for situational ethics (Howard & Irani, 2019; Munteanu et al., 2015), we see how current structures filter too broadly. As a result, risks that are not physically damaging but harmful nonetheless are inadequately recognized and poorly addressed. For example, a now retracted article examined young vascular surgeons’ public social media profiles for “unprofessional” content and unfairly focused their critique on women surgeons for how they dressed in their photos (Hardouin et al., 2020; Shaprio, 2020). Despite its sexist focus with problematic methods, the study was approved by an institutional review board. Further, our findings in Section 3.4.1.1 point out how current HCI researchers are reflecting on the shortcomings of standard risk evaluations. They also highlight suggestions for amending our understanding of risk to account for possibilities of increasing marginalization. Therefore, research ethics evaluations at local levels and collective attitudes in HCI must have stronger protections of marginalized people. One noteworthy example in HCI is the “Feminist Data Manifest-No,” a document that rejects dangerous data practices and makes commitments to a non-exploitative paradigm of data usage (Cifor et al., 2019). The authors of the Manifest-no initially crafted the list through an institution-hosted workshop, and so we call for expanded organizational support to host, fund, and celebrate local labor pushing for stronger institutional ethics.

As we heard from current HCI researchers, participants are not the only group at risk of exploitation in research: researchers may also exploit other researchers. In recognizing that researchers with marginalized identities should not be responsible for protecting their own communities from harm, our findings and other work provide guidance on how to reduce this form of exploitation. In *Crippling Emotional Labor: A Field Guide*, Amy Gaeta, who at the time of this study was a PhD candidate in English focusing on feminist disability approaches to Science, Technology and Society (STS), makes recommendations for researchers of marginalized identities: "We must analyze when we are being valued as a person or valued as resource and recognize it's not always either/or" (Gaeta, 2019). From there, Gaeta makes suggestions for researchers who experience marginalization on how to handle possible exploitation, such as distinguishing emotional labor from emotional support, setting boundaries, and not feeling guilty for saying no. For those who want to ask for emotional labor from others, Gaeta recommends asking early and being transparent about not wanting to exploit their help. Part of mitigating the exploitation of researchers involves removing as much burden as possible from a request. In line with HCIR14's recommended questions for reducing exploitation in Section 3.4.2.1, researchers should ultimately distinguish between what the requester can learn on their own—e.g., through searching for past conversations or resources online or reading literature—and what information must come from the requestee.

It is also important to note that technological innovation does not always have to lead to exploitation; there is opportunity for novelty in HCI while not taking advantage of other researchers and participants. Participant responses in Section 3.4.3 provide some guidance for how to do this, by openly talking about the messiness of research and understanding the limits of what technology can accomplish. This second piece of advice is particularly crucial for those seeking both novelty and impact. Advances in technology can and have had great benefits for users who experience marginalization, but there is real danger in believing that these achievements will “fix” the problem. So, we hope that HCI researchers continue to push technological boundaries while also understanding the limits of their real impact.

While researchers can and should find ways to make their practices less exploitative, efforts to resist exploitation in HCI research must also happen at a structural level. It is unfair to place sole responsibility onto individual researchers to change behaviors that have been conditioned by the norms of the field. As shown in Section 3.4.3, this influence places much burden on marginalized researchers especially and can govern how researchers interact with participants. While efforts such as the SIGCHI Social Impact Award incentivize research that values equity and not just technology innovation, there are problems when our governing institutions stop at these rewards without looking at the deeper impact. Researchers are led to believe that only individuals at the height of their careers can achieve this status, and further, only one to two people in the expansive field of HCI receive such awards each year. As a result, recognition for equity and justice driven research is scarce, further isolating those already making efforts to transform the field. We should celebrate and continue to recognize individuals who are doing good work, but we are just not doing nearly enough to ensure that more people can do this work and be rewarded for it throughout their careers.

There are various dimensions to the tension of exploitation, not only in terms of who is exploited but also regarding what can be done to address such unfair burdening. The experiences of the HCI researchers in our study illustrate how this plays out in HCI, including the work these researchers do to mitigate that exploitation. Even as they do this work, pursuits of impact through novelty can work against aspirations of equity and justice. This can result in short-term harms to participant or researcher well-being. Further, when HCI research claims a technical solution based on a shallow understanding of a complex societal problem, our research community risks misappropriating resources to ourselves and away from the very community and grassroots organizations that are most able to address them. To mitigate this, our field must learn to be more honest about the limitations of our understanding and solutions. We can learn to be better partners to the communities involved in our research from current members of our community who are modeling this kind of work (e.g., Erete, 2015; Ghoshal & Bruckman, 2019; Hui et al., 2020).

Finally, one common approach to preventing researchers from exploiting participants with marginalized identities is gatekeeping or preventing researchers from working with participants with different identities. In the next section, we explore the difficulty and complexity in doing so and how it contributes to further marginalization.

3.5.2 The Tension of Membership

The debate over what a person's identity allows and/or prohibits them from doing has been long discussed in non-HCI spaces by scholars of color. Our membership related findings link to "A Black Feminist Statement" created by the Combahee River Collective, a group of Black Feminists that comes from a history of survival and liberation of Black women, centers the rights and oppression that Black women face specifically, and is dedicated to fighting injustices that are responsible for the oppression of marginalized people (Combahee River Collective, 1977). In their statement, they write about how membership grants a uniquely powerful perspective on how that individual is systematically oppressed: "We believe that the most profound and potentially most radical politics come directly out of our own identity, as opposed to working to end somebody else's oppression" (Combahee River Collective, 1977, p.212). While holding this as true, we add that this does not inherently mean that non-members of a marginalized group cannot help with their fight against injustice. It is through this lens that we understand and explore the tension of membership: supporting those on more oppressed points along specific axes of oppression without overstepping our bounds. Specifically, we extend membership conversations in HCI by discussing 1) the limits of what marginalized researchers can make claims about and opportunities for reflection, 2) why HCI researchers should not prevent researchers from working with marginalized group solely based on a person’s identity, 3) what is needed for researchers who do not experience marginalization in that given context to engage in such work, and 4) structural recommendations for HCI to move beyond identity politics without erasing marginalized experiences.

In our findings, the HCI researchers we heard from identified different levels of membership in their own work: some felt they shared identities and experiences while others did not. They indicated the difficulty of varying levels of membership in two ways. First, participants said that membership is helpful to research by providing insight only possible through shared experience, but it is also not a guarantee that that work will be done with care. Second, they pointed out that non-membership should not be the sole reason that researchers cannot work with marginalized groups, but it should come with extra reflection over the researchers’ possible impact and the space they take up as guests.

As a majority of the HCI researchers we heard from in this study self-identified as having one or more marginalized identities, many of our results raise recommendations for researchers who experience marginalization. Commonalities between researcher and participant can be helpful as HCI researchers in our study experienced many benefits of shared membership with participants such as helping them establish trust and rapport. However, those researchers, others engaged in the research, and their audience must also be aware of their limits. For example, in Section 3.4.2.2, some HCI researchers discussed how they could never fully connect with the varied makeup of their participants' identities, and so they avoided claiming that they could completely and accurately represent the experiences of participants in their studies. Membership also does not guarantee that a researcher cannot make harmful decisions. HCIR15 pointed out in Section 3.4.2.1 that they were concerned that readers would be less willing to criticize their work because of the membership make-up of their research team. In addition, members of marginalized groups can do and have done harm to their own communities. The concept of homonormativity provides one example of this form of harm and inter-community gatekeeping. In short, homonormativity manifests as valuing, conforming to, aspiring to, and politicizing the ideals of a heteronormative way of living and thinking (Duggan, 2002; Halperin, 2012). As a result, homonormativity has created a commonly accepted monolith of what it means to act as and look like an LGBTQ+ person, and those who fit the mold discriminate against any deviations from the norm.

Similar to some HCI researchers in this study, readers with marginalized identities might face discomfort over how much to use their identity as an asset in their work versus how much to question what it allows them. We emphasize here that these recommendations to reflect on individual limits are not meant to diminish their lived experiences in any way, but rather to ask these researchers to identify personal boundaries given their positionalities to protect other marginalized people. To better understand the unique experience of researching with communities with shared marginalized identity, we draw from Villenas' discussion of her own position as a researcher working with a community that she shares membership:

> "Here is my own dilemma: as a Chicana graduate student in a White institution and an educational ethnographer of Latino communities, I am both, as well as in between the two. I am the coloniz*ed* in relation to the greater society, to the institution of higher

> learning, and to the dominant majority culture in the research setting. I am the coloniz*er* because I am the educated, ‘marginalized’ researcher, recruited and sanctioned by privileged dominant institutions to write for and about Latino communities. I am a walking contradiction with a foot in both worlds — in the dominant privileged institutions *and* in the marginalized communities. Yet, I possess my own agency and will to promote my own and the collective agendas of particular Latino communities.” (Villenas, 1996, p. 714)

Villenas’ “foot in both worlds” will likely resonate with other marginalized researchers, and she provides further guidance for those who might feel uneasy. In her reflections over this position, she discusses how researchers can further act as colonizers. She warns against two possible ways that researchers can be colonizers: first, leveraging a researcher’s authority and position to make definitive claims about participants without their input, and second, when researchers fail to reflect on their own privileges in the process. Villenas provides her own approach to reflecting upon her position:

> “I needed first to ask myself, How am I, as a Chicana researcher, damaged by my own marginality? Furthermore, how am I complicit in the manipulation of my identities such that I participate in my own colonization and marginalization and, by extension, that of my own people — those with whom I feel a cultural and collective connectedness and commitment? For these reasons, researchers must examine how their subjectivities and perceptions are negotiated and changed, not only in relation to the disenfranchised community as research participants, but also through interactions with the majority culture.” (Villenas, 1996, p. 721-722)

In this way, researchers who work with people they share experiences of marginalization with must balance their own simultaneous positions as colonizers and colonized. Villenas leaves the reader with this: there is power and strength in the middle, in the both/and where these identities as colonizers and colonized are intertwined, or, as Fine describes it, working the "Self-Other hyphen" (Fine, 1994). Villenas' conclusion might resonate with readers who experience marginalization:

> "My answer to the ethnographer-as-colonizer dilemma is that I will not stop at being the public translator and facilitator for my communities, but that I am my own voice, an activist seeking liberation from my own historical oppression in relation to my communities" (Villenas, 1996, p.730).

Villenas' account provides an example of how one researcher has unpacked their identities, and we push marginalized researchers in HCI to take it as inspiration to critically explore their own identities.

HCI researchers in this study also described the roles that various kinds of gatekeeping have in research with marginalized people, specifically focusing on the gatekeeping that researchers do to other researchers. Based on the experiences of participants in this study, we argue that membership should not be used as a gatekeeping device. Determining who can do what research stifles the production of knowledge that marginalized people already lack and deserve. Limiting research with marginalized people to only those who have some form of membership is ultimately harmful. Doing so would only make HCI's focus on Western, Educated, Industrialized, Rich, and Democratic (WEIRD) participants even worse, given that our community is also not yet as diverse as we hope to be (Sturm et al., 2015). Additionally, leaving the responsibility to do work with marginalized groups on researchers who experience marginalization is not only a form of epistemic exploitation, but it may ultimately pigeon-hole marginalized researchers into focusing solely on marginalization if no one else will do the work. We must be particularly attentive to this second piece because a continual cycle of asking marginalized researchers to carry the weight of entire research agendas while simultaneously undervaluing that work would inevitably increase inequities in academia, including burnout and low levels of retention among marginalized academics, even further (Aguirre, 2000; Daley et al., 2006; Lloyd-Jones, 2014).

Recommendations for HCI

Ultimately, we take issue with assumptions that members of a marginalized group can do no harm, while non-members only do harm. Neither can necessarily hold true. Rather than using a researcher's identity as *the* metric for the appropriateness and validity of their work, readers and reviewers should evaluate what considerations the researcher made throughout their research process *in addition to* remaining attentive to the author's positionality in the study context. Did the researcher note if and how they made ethical considerations? What steps did they take to ensure they protected participants from both high-level and smaller-scale harms? Membership can provide expertise that supports researchers in making appropriate choices, but it is not the only way to make those choices, and the entire research community benefits when publications document the choices made.

As we heard from participants in this study, researchers who experience marginalization are often asked to do more, such as educating readers about "what transgender is" from Section 3.4.2.2. So, we find it important to call out the relationship of membership and invisible, uncompensated labor. While we call for researchers to share the ethical considerations they took in their work, this must also not become a justification for requiring marginalized researchers to do more work to teach other HCI researchers how to make such choices.

Ignoring work that is often asked or required of researchers who experience marginalization and not others would only further contribute to epistemic exploitation in HCI, a practice already present and documented today (Grady et al., 2020). As it stands, our current structures make it so that the work required to build more inclusive, equitable research environments and dismantle systemic barriers to research fall unevenly on marginalized researchers. Even more condemning, these efforts to improve our field for everyone are taken for granted and ignored. Too many Black scholars have documented the discrimination and isolation that Black researchers, and especially Black women, in computing face for such behavior to continue (Black in Computing and Our Allies for Equity and Fairness, 2020; Rankin et al., 2020). Because of this, our recommendations for the HCI community must occur in tandem with changes that better recognize marginalized scholars for their work and/or decrease the burden of labor of what we currently ask of them.

Part of the process to lessen or share additional labor must involve action from HCI researchers with privilege, and there are many opportunities to reflect upon their levels of membership and take action. Thus, we position this work alongside previous literature calling for better, more intentionally intersectional HCI research, specifically the Intersectional Computing framework introduced by Thomas et al. (Rankin et al., 2020; Thomas et al., 2018). Serious work needs to get done, ranging from individual-level attention to the inequalities that people unlike them are facing today and the larger structures responsible for such injustices to an understanding of micro-level interactions with those around them. This means more than just an awareness but a deep, probably uncomfortable journey toward learning about what their membership has granted them and their relationships with systemic racism, capitalism, patriarchal society, ableism, homophobia, transphobia, and many more.

There are clear and practical ways for HCI as a research community to make more space for thoughtful documentation of research processes. To support full discussion of the ethics considerations in research, organizers of publication venues might consider expanding or eliminating page limits or not counting sections of papers that discuss ethical or inclusion aspects toward page limits. This would allow for more detailed discussions of the processes and care that were taken to protect marginalized participants, without sacrificing space for results or research contributions. The Interaction Design & Children conference (IDC) already requires a “Selection and Participation of Children” section[7] that does not count toward its page limits; this could be a model that venues wishing to retain page limits could follow. Such feasible changes would go a long way in prioritizing work that engages in thoughtful reflection. In addition, authors will not be placed in the difficult position of choosing between documenting their ethical considerations and other crucial parts of their work.

The tension of membership contests beliefs about researchers who share identities and experiences with participants they work with. Researchers with shared marginalized identities deserve to have some authority over their collective experiences with participants, as membership can support expertise in making choices; additionally, they must also recognize the limits of what they can claim to understand. However, recognizing the benefits and limits of membership should not automatically lead to rejecting, ignoring, or taking marginalized voices for granted. Even if membership cannot be constructed as a monolithic, all-encompassing

---

[7] From the IDC 2020’s submission page on why they require such a section, “Designing with and for children comes with challenges and responsibilities. The IDC community is keen to include children voices as well as to protect their rights and promote the ethical inclusion of their perspectives in research. Papers must include a section “Selection and Participation of Children” in which the authors of the paper should describe how children were selected (if there were no children simply write – no children participated in this work), what consent processes were followed (i.e. did they consent and if so what they were told), how they were treated, how data sharing was communicated, and especially any additional ethical considerations.”

experience for all, there is opportunity to learn from the collective wisdom of people with shared experiences (Rankin & Thomas, 2019). Further, such uses of a researcher's identity to diminish the knowledge they contribute is testimonial injustice (Fricker, 2007). As some HCI scholars have documented, such an experience is in fact violence against fellow researchers and reflects a shameful history of practices in our field (Ymous et al., 2020). Considering all of this, there needs to be a careful balance between respecting researcher experiences and following their lead without question, assuming that anyone is exempt from doing harm to marginalized people.

In presenting this tension, we emphasize the need for researchers to further interrogate identities and the roles they play in research. For researchers, the partial membership they may have with research participants can be an important consideration—but far from the only one—in whether and how to proceed. We recommend that HCI researchers understand membership as a spectrum of shared experiences, while also avoiding conceptions that full membership is even attainable when considering intersectionality. As part of this process, researchers must work to understand their own identities and how they have shaped their experiences and approaches to research — something we ourselves have struggled with in revisions of this paper.

3.5.3 The Tension of Disclosure

Experiences of the HCI researchers in this study indicate confusion around when it is appropriate to ask authors to be reflexive and what authors should include in positionality statements. While we asked participants to talk about their experiences with reflexive or positionality statements, many spoke about requests for identity disclosure. These experiences indicate that while there is a theoretical difference between reflexivity and positionality, this distinction does not reliably carry over to current practices.

The tensions of membership and disclosure are closely related. Reflexivity and positionality statements can help people understand the strengths and limitations of the work, which clarifies the author's position, but they can also open up researchers to discrimination or harm. Basing judgements and decisions on an author's membership might help communicate researcher motives for doing work with marginalized people, but it would also require researchers to disclose their identities publicly. If the HCI community chooses to govern who can or cannot do certain kinds of research, asking for this information without continuing to marginalize researchers presents a major dilemma that requires a deeper engagement.

In the past, HCI researchers have made calls for expanded reflexivity and self-disclosure practices. For instance, Bardzell & Bardzell describe reflexivity as a key component of their Feminist HCI and define it as an "ongoing self-questioning about whether the research is delivering on its ambitions to be feminist, improve human quality of life, and undermine rather than reinforce oppressive social structures, etc" (Bardzell & Bardzell, 2011, p. 683). Schlesinger et al. provide more guidance, calling for statements not necessarily rooted in author identities and "would help the community better interpret a publication, like a privilege, ethics, or values disclosure" (Schlesinger et al., 2017, p. 5421). The tension of reflexivity and positionality builds upon previous calls by providing more granular reflection tools for researchers and reviewers through Table 4. Here, we further explore the nuances of disclosure requests, emphasizing that reviewers who may ask for information about the authors should be explicit about what they are looking for and why.

In Sections 4.2.1.2, 4.2.2.2, and 4.2.3.2, we highlight different dimensions that must be considered in calls for reflexivity and positionality. First, disclosing certain identities or experiences can have a range of social consequences, and positionality practices within HCI cannot ignore these repercussions. Next, setting an expectation for positionality statements might end up outing people who are not comfortable being outed, under threat of barriers to publication, career advancement, or conflict in their lives outside of work. Third, the HCI research community may consider positionality statements that describe author identities collectively rather than individually, though this of course creates challenges in solo-authored papers. Further, to reiterate a point discussed in the tension of membership: the community should take care not to rely on positionality statements and membership as a shortcut for validating (or invalidating) work with marginalized people.

Additionally, our results point out benefits and disadvantages to identity disclosure. Some participants in this study discussed how disclosing their identities helped to establish greater trust of the researcher and in the research process, benefitting marginalized people who participate in research. Disclosing one’s identity to participants, though, is a personal choice and fellow research team members, collaborators, and reviewers should not pressure others to out themselves. For authors, choosing whether to include a positionality statement is difficult, as they cannot fully anticipate how audiences might respond to them. Further, because disclosure of a marginalized identity can open researchers to unconscious biases or more overt discrimination, pressuring marginalized researchers to include a positionality statement comes with potentially severe repercussions. These benefits and potential costs of disclosure cause researchers to face a tension in choosing whether to and how to discuss the ways their identities have influenced their work. As seen in Section 3.4.2.1, participants of our study have experienced expectations of disclosure under the pretense of being reflexive, to out themselves for their work to seem legitimate. Asking researchers to choose between disclosing—increasing the chance of publication but also increasing the chances of judgment or backlash—or not disclosing—decreasing the chances of publication but reducing the risk of backlash—can further abuse the already marginalized. As our results point out, researchers experience discrimination not so much for the inclusion of a reflexive statement but more for the content.

However, we cannot assume that a lack of reflexivity or positionality protects authors from these biases. As seen in the experiences of participants in our study, a lack of a reflexive statement can lead to reviewers and other researchers making assumptions about researchers' identity and membership (or lack of membership), often to frustrating effect. We encourage reviewers and others not to make any such assumptions; doing so may force a researcher to out their identities just to defend their work.

Highlighting this tension of disclosure does not mean that authors cannot include positionality statements that disclose their identities; rather, we push back against a culture of reflexivity statements as a norm. The decision to disclose should be up to the individual researcher, and not a consequence of an expectation or request from a reviewer or research team. However, some of the HCI researchers in our study have experienced these outside pressures to disclose, and they report that such requests are increasing in prevalence. As a result, we hope that individual researchers who might want to disclose their identities and reviewers who might want such information consider the questions in Table 4, influenced by themes in this work.

Researchers Considering Disclosure	Reviewers Requesting Disclosure

Why do you wish to disclose? Is it only to satisfy someone’s curiosity? Is it to promote social justice or act as a role-model for other researchers? Is it to help share what you see as the strengths and limitations of your work? Is it to provide legitimacy to your work? Are there mechanisms in place that would allow you to reverse your decision? Have you considered disclosing to reviewers only rather than permanent disclosure in print? How might your disclosure influence how readers perceive your work? What are the potential outcomes of disclosing your identity?	Why are you asking for disclosure? How might it influence your perceptions of the work? For what reasons? What assumptions are you making about the authors’ identities? How might the authors be harmed through such a request? Is there other information that could address these needs? (e.g., can you instead look to the authors’ ethical considerations to provide what you are looking for?) How might this knowledge affect how you perceive their contributions?

Table 4. Reflective questions for authors and reviewers considering disclosure

Individuals should be able to decide whether or not they want to disclose their own identities, but it is hard to disentangle whether they are doing it for themselves, to please a reviewer, or because they have seen similar statements elsewhere. In HCI, there is little work that explores the nuance of reflexivity and positionality or documents the real-world consequences that many researchers who experience marginalization face when they disclose their identities. We hope that these guiding questions can help both researchers thinking about disclosure through a positionality statement and reviewers considering asking for one to reflect on the nature and potential impacts of such a decision.

3.5.4 The Tension of Allyship

Across our interviews, survey responses, and our own hopes of supporting marginalized people in research, we see parallels with the goals of allyship. Allyship efforts in and out of academic contexts leverage power for social progress, and we can use allyship as a way to understand how we as HCI researchers can do better and what barriers to avoid. In the following section, we outline key components of allyship, and we propose an allyship-oriented approach to research with marginalized people, one that is explicitly in opposition to systems of oppression and asks individual researchers to engage in a constant cycle of critical self-reflection.

Especially in HCI, research has the power to help groups of people by building and designing systems, tools, and knowledge. However, sometimes what we as a field create ends up—regardless of our intentions—furthering marginalization, harming those that we try to help, and/or prioritizing researcher agendas ahead of the priorities of marginalized people. In research and beyond, allyship provides one framework for working with marginalized people. Scholarship on allyship has explored the nuance involved in being an ally, revealing that this form of work cannot be done haphazardly (Powell & Kelly, 2018; Leonard & Misumi, 2016; Kluttz et al., 2019). In the following section, we draw upon criticisms of allyship from previous scholarship and the 24 HCI researchers in this study to demonstrate the tension of allyship: not all research that claims to be allyship is allyship and, simultaneously, all research should be allyship. The tension of allyship encompasses many of the concerns in each of the previous tensions; addressing issues of exploitation, membership, and disclosure are all involved in confronting the tension as a whole.

There are actions that researchers can take to address the potential “empty” allyship in research the HCI researchers in this study were wary of. In addition to the suggestions we discuss in the sections above, researchers should avoid pushing potentially beneficial, but potentially unsustainable, technologies onto people without the researcher’s ongoing support or a plan to develop sustainable practices around their use. To address this, researchers should consider the long-term effects of their presence and mediate any harms that might occur from their departure. For example, researchers could communicate when and how they will leave at the beginning of a study to set clear expectations for participants. In this way, researchers might consider integrating reflections on their impact into their research processes.

Further, we draw from the work of Boaventura de Sousa Santos, who has written extensively about embracing and working with alternative ways of knowing, specifically epistemologies that are not centered around the Global North. While de Sousa Santos challenges a singular, Western way of knowing, he explains that these ideas should not be dismissed altogether (de Sousa Santos, 2014). Instead, Santos calls for the “expansion of the present,” an approach that embraces other forms of knowledge *in addition to* how the majority deems what is knowledge and what is not. Drawing from these ideas, our vision of equitable allyship does not mean the absolute rejection of researchers with privilege, but instead the expansion of what it means to include marginalized people in research. We believe that as a community, we should not exclude others from doing certain kinds of research and solely use membership as a metric for good or bad work. Not using the power of allies to elevate marginalized people would be a waste in the pursuit of justice. Rather, the entire HCI community should strive to better involve and fairly interact with marginalized people in research, both as participants and researchers.

Our results resonate with discourse in other fields, demonstrating overlaps with HCI and opportunities to further learn from them. Challenging the notion of universalism is deeply rooted in Disability Studies (Imrie, 2012) and Feminism (Franks, 2002), and similarly, we found that matters of allyship and marginalization require an acknowledgment that there are no blanket solutions (or even possible solutions, for that matter). As researchers, however, we cannot let these barriers become restrictions. Also, consistent with CBPR, PD, and ICTD views on equity, justice, and impact, HCI researchers can strive to build systems and knowledge that are acts of allyship; however, we must be certain that what we push on people has been well thought through and done with the knowledge that these are what they want. Researchers should also be wary of overclaiming their power or impact on their participants; just because they might be building knowledge or tools intended for their benefit does not guarantee that their contributions are warranted or socially progressive.

Our work further builds upon a growing effort to think critically about how researchers engage with marginalized people. To highlight one example, Antle identified five questions for researchers to ask when working with vulnerable populations: 1) "How can we feel relatively certain that we are providing benefits to the population we are working with?"; 2) "Given the requirements of many university ethics boards, how can we work with children who may most need help but are least able to give assent?"; 3) "How do we find a balance between conducting rigorous research and ensuring that our research does not harm the children we work with?"; 4) "How do we manage children's expectations and attachment with the research team in ways that will minimize any emotional damage to the children?"; 5) "What will we leave behind when the research ends?" (Antle, 2017, p.75-77). While Antle's questions are specific to child-computer interaction, they also illuminate transferable and relevant questions around understanding impact, accounting for ethics under existing structures, and reevaluating harm and justice as a part of our research processes.

Finally, an understanding of allyship and working with marginalized people would be incomplete without acknowledging the labor and knowledge from many activists, a movement already present in HCI (e.g., Benjamin, 2020; Bennett & Keyes, 2019; Dillahunt & Veinot, 2018; Muller, 2003; Parker et al., 2012). There are numerous opportunities and lessons to learn from. For one, definitions of allyship that come from some of the most oppressed voices in society can be the most revealing and must be centered in these conversations. To address why this might be the case, we again turn to the Combahee River Collective's *A Black Feminist Statement* as they stated "We might use our position at the bottom, however, to make a clear leap into revolutionary action. If Black women were free, it would mean that everyone else would have to be free since our freedom would necessitate the destruction of all the systems of oppression" (Combahee River Collective, 1977, p. 215). Roxane Gay, a writer, activist, and social commentator, built upon this point to describe the potential empty promise of allyship with Black people (Gay, 2016):

> "Black people do not need allies. We need people to stand up and take on the problems borne of oppression as their own, without remove or distance. We need people to do this even if they cannot fully understand what it's like to be oppressed for their race or ethnicity, gender, sexuality, ability, class, religion, or other marker of identity. We need people to use common sense to figure out how to participate in social justice.
>
> Don't tell us about your racist uncle or grandfather or sister or cousin. Don't try to unburden yourself of guilt that isn't yours to carry. Actively listen when marginalized people tell you about their oppression—don't offer your pity (which only helps you) and don't apologize. Listen and do your best to understand what it feels like to live with oppression as a constant. Speak up when you hear people making racist jokes. Speak up when you see injustice in action. Inform yourself about your local law enforcement and how they treat people of color. Vote. Take a stand instead of waiting for absolution from people of color. We don't have that kind of time. We're fighting for our lives."

Gay's writing highlights crucial ideas and criticisms of allyship, such as ensuring that the focus is on the experiences of marginalized people and investing in issues that might not be our own.

The piece is clear in its call for action as opposed to passive, tacit support, and it also displays an exhaustion with empty allyship as Gay lists off the many ways that allies can try and have tried to refocus attention onto themselves. In addition to these learnings, several organizations outside of academic circles have put forth allyship-oriented guides that provide opportunities to learn from. While we provide short summaries, we urge readers to seek these resources directly:

> **Design Justice Network Principles:** Design Justice Network centers marginalized voices in the design process and puts forth ten principles. Among others, they call for designers to "prioritize design's impact on the community over the intentions of the designer," "view change as emergent from an accountable, accessible, and collaborative process, rather than as a point at the end of a process", and "look for what is already working at the community level [... and] honor and uplift traditional, indigenous, and local knowledge and practices" before pursuing novelty (Design Justice Network, 2018).
>
> **Accomplices not Allies:** Indigenous Action Media criticizes the model of allyship for the ways that some people are more caught up with being identified as an ally than the deep, meaningful, and ongoing engagement that is needed. In response, they turn to accomplices instead and recommend that accomplices do research before reaching out to communities of marginalized people, not do work to absolve oneself from guilt or shame, be ready to be held accountable for one's actions, and not to pursue accomplices as an identity (Indigenous Action, 2014).
>
> **#TalkAboutTrayvon: A toolkit for white people on the fifth anniversary of Trayvon's Death:** Black Lives Matter created this toolkit that calls for white allies to speak out against racism on their platforms (social media, personal, etc.), engage with other white or non-oppressed

people, and take action (e.g., give money, educate themselves, and actively advocate for the rights and equal treatment of others) (Black Lives Matter, 2017).

Ethical Guidelines for Research Involving Transgender People & Communities: The Canadian Professional Association for Transgender Health (CPATH) created procedures for researchers to take when doing trans-specific research. In particular, they advocate for researchers to actively consider possible impact (both positive and negative) of their work, account for concerns over privacy and revisiting trauma, involve trans people in all phases of the research process, and help trans people become sustainable in becoming researchers (Bauer et al., 2019).

Looking across our results, critical discussions of allyship, and recommendations put out by activist groups, there are commonalities that contribute to an allyship-oriented approach to HCI research, summarized in Table 5. Our work both echoes recommendations from current literature and activist guides and translates them into lessons for HCI as a field. Specifically, we make two additions to understanding research as allyship. First, we provide examples of actions and considerations researchers can take to balance equity and justice with impact, discussed through the tension of exploitation. Next, we call for an approach to research that avoids unproductive conversations about identity politics. As Collins and Bilge wrote on intersectionality, bringing up matters of identity cannot mean an immediate end to conversation, but instead act as a traversal point for further inquiry (Collins & Bilge, 2016). Situating these ideas into this work, this manifests as gatekeeping research agendas and requiring identity disclosures, shown through the tensions of reflexivity and positionality and membership. Moving past identity politics does not mean a complete denial of the historically rooted oppressions that some people face; rather, this approach challenges over-simplifying groupings by membership status while still understanding how different experiences shape and reshape us. As mentioned before, this is a both/and approach rather than an either/or one. For researchers who have privilege in any number of axes of oppression, this means considering identity-based experiences as an important point, but not the sole factor for deciding whether and how to proceed with research. These researchers also have the responsibility of pushing through difficult conversations especially when it comes to identity.

Allyship in…		
Our Results	**Previous Allyship Literature**	**Activist Guides**
Works towards equity and justice in addressing exploitation of both participants and researchers Moves past identity politics both in terms of gatekeeping who can do what research and asking for identity disclosure	Redistributes power from those with it to those without (Iyer & Leach, 2009; Brooks & Edwards, 2009) Avoids tokenizing marginalized people (Russell & Bohan, 2016) The majority challenges the status quo (Subašić et al., 2008; Tatum, 1994) Centers the agendas of marginalized people (Russell, 2011; Evans et al., 2005)	Understands and prioritizes impacts on marginalized people (Design Justice Network, 2018) Embraces the ongoing process and lack of endpoint (Design Justice Network, 2018) Avoids pursuing novelty for novelty sake (Design Justice Network, 2018) Fills real gaps, not ones created by researchers for researchers (Design Justice Network, 2018) Rejects ally as an identity (Indigenous Action, 2014) Prioritizes taking direct, meaningful action (Indigenous Action, 2014) Leverages privilege and power (Black Lives Matter, 2017) Accounts for and anticipates potential harms beyond traditional

		conceptions of harm (Black Lives Matter, 2017) Works with actual target communities (Bauer et al., 2019) Considers sustainability of research within the communities (Bauer et al., 2019)

Table 5. Summarizing across our results, previous literature, and activist guides

While we have described various recommendations for individual-level change, allyship cannot rest solely on each researcher. The HCI community requires a larger-scale transformation to be sustainable. Allyship requires a comprehensive effort to dismantle systems of oppression, structurally and collectively.

To provide an example of the dangers in having a singular focus on one issue or one axis of oppression, we return to the concept of homonormativity from Section 3.5.2, where we demonstrated how homonormativity influences individual LGBTQ+ behavior and thinking. Homonormativity shapes institutions as well. For example, after the United States Supreme Court decision enacted marriage equality, policymakers and administrators made changes that helped homonormative individuals at the expense of those who do not fit into a normative ideal (Daum, 2020). Daum writes: “the focus on sexual orientation operationalized as a single axis characteristic (heterosexual or homosexual)… led many policymakers and administrators to homogenize LGBTQ individuals thereby rendering poor, queer, and trans people of color illegible in the marriage equality context. In addition, once marriage was legalized, most policymakers and administrators moved to treat LGBTQ individuals the same as heterosexuals and gender-conforming individuals without recognizing that promoting homonormativity marginalizes LGBTQ individuals who are unable or unwilling to conform to these expectations. *Thus, while opening the institution of marriage may advance equality, it also facilitates the ongoing marginalization and illegibility of uniquely vulnerable intersectional individuals within LGBTQ communities*" (emphasis added Daum, 2020, p. 118). There was nothing wrong with fighting for marriage equality; the issue arose when marriage equality became the sole focal point and made sweeping characterizations about how LGBTQ people achieve equality based on a single, normative understanding. We highlight this example to act as a cautionary tale of what can happen when well-intentioned allies, or even members of a community, focus on one group or issue without considering the expansiveness within identity.

Simultaneously, the HCI community cannot ignore specific injustices either. It is essential that we interrogate systemic racism, for example, especially with HCI's insufficient history failing to recognize the value of contributions about race or ethnicity (Schlesinger et al., 2017). As Ogbonnaya-Ogburu et al. point out, "As we become concerned with new dimensions of diversity and inclusion, we cannot dilute efforts to address race. All too often, panels and committees pass as "diverse" because they contain non-males. Race is overlooked as a category of diversity" (Ogbonnaya-Ogburu, 2020, p. 265). In light of this, we raise perhaps the most important limitation of our work: where we look across marginalization in the macro, we overlook specific instances of injustice. While we maintain that each of the tensions that we have identified affects researchers who experience marginalization in some way, we cannot make definitive claims about to what extent. Our failure to probe further in our surveys and interviews about how the specific nuances of individual identity and experience change how a researcher experiences each tension differently serves as a major oversight that we hope researchers consider when reading our work. From this, our final challenge to the HCI community, both as a group of individual researchers and a group of institutions with great power, is to avoid treating the tensions laid out in this paper as monolithic experiences and to think about how the effects of each are specific to your own identity, research project, career, institution, epistemologies, values, and more. For instance, while everyone is culpable of exploiting researchers, are some researchers more susceptible to tokenization if their identities are more readily visible (e.g., BIPOC, women)? How are our practices informed by our own racisms? How might people with identities whose public disclosure would put them at risk of physical and emotional abuse react to a request for expanded positionality? And further, what can we do about this? What can you, as an individual HCI researcher, do in response?

While concepts of reflexivity, membership, and exploitation are significant considerations for research in their own right, they also all contribute to an overall commitment and approach to doing research with marginalized people. Thinking in this way is both just and imperative, especially if HCI researchers continue to choose to engage with marginalized people in their work. We hope that researchers who do make this choice consider how their work might or might not act as allyship and, on a larger scale, contribute to social justice. Many of these ideas are not new, in fact many have been long discussed and often by authors of color. However, little work has situated these conversations with the context of HCI, where we design, develop, and/or influence systems that have the power to hurt and/or heal.

3.5.5 Limitations & Future Work

The suggestions we highlight for improving the experiences for participants come from the perspectives of HCI researchers of both marginalized and privileged identities. Our results offer insights into the steps researchers take to engage more equitably and justly with participants, how researchers affect other researchers, and how they are affected by the field. However, that focus also decenters the experiences of marginalized participants in HCI research. Our reliance on researcher experiences likely biases our recommendations in ways we do not know, and suggestions directly from participants in HCI research might highlight other strategies. Future work should focus on marginalized participants' experiences with HCI research and HCI researchers, prioritizing engagement with participants directly. One opportunity to explore this is through a concern raised by some researchers in this study about giving little back to participants. While this paper describes some researchers' perspectives, we wondered whether participants would agree and, further, whether researcher beliefs about what participants want from studies align with what participants actually seek to get from their participation. Further work should examine what participants in HCI research perceive they are getting out of the research process (e.g., Kolovson et al., 2020). Researchers might add questions to interview or survey protocols asking what participants took away or learned from participation or their reasons for taking part in the study.

We also acknowledge that, like most HCI work, the United States and Global North are contextual points of focus throughout this paper. Because some survey responses were anonymous, we cannot make definitive claims about the researchers who participated in our study; however, we did not make strong enough efforts to recruit and engage with participants outside of the contexts we were familiar with and non-WEIRD participants. We invite future work to explore HCI research with marginalization in locations outside of the Global North and how cultural differences might lead to a similar or even different set of tensions.

Additionally, this work addresses engagement with marginalized people at a macro-level and does not address the specifics of how different contexts of marginalization call for different considerations. While we reject a universalizing, blanket approach to HCI research involving marginalized people, we hope researchers can draw on this work as a starting point for understanding the nuances of their specific research settings. More recent work that blends research with activism has examined much-needed, more precise areas of HCI research such as how HCI handles race and systemic racism (Ogbonnaya-Ogburu, 2020), a critique of ableism in HCI (Ymous et al., 2020), trans competent interaction design (Ahmed, 2018), and guidelines for gender inclusivity (Scheuerman et al., 2019). In addition, our discussion of the four tensions is by no means conclusive; there is much room for further understanding and development of better practices. For example, our work did not directly examine invisible versus visible identities.

Finally, as we reflect upon the journey this paper has taken us on, we wish to share the messiness involved in our process. With hindsight, we have seen how overly ambitious our goals for this project were. To take on the topic of marginalization as a whole requires extensive engagement with all facets of oppression, and we were not prepared enough for this at the beginning of the study. Because of this, our results are in no way definitive or exhaustive; the work fighting for marginalized people in HCI is far from over. Research, as we have demonstrated, is an ongoing process, one that participants, researchers, and the HCI field should collectively engage in together.

3.6 Conclusion

Researchers interested in working with marginalized people may be dismayed by the tensions of exploitation, membership, disclosure, and allyship. As a reader, you may wish that this paper could tell you exactly what steps to take to ensure ethical research. However, the overarching theme across the study participants' experiences is that there is no one, perfect way to do this kind of research, and so we refrain from suggesting that there is or even could be such a set of steps. Rather than prescribing a checklist for doing research the “right” way, we hope that you will consider the situational needs of the project, potential participants, and others affected by the work, including the research team.

As our findings detail, there are several possible actions that researchers can take, from consulting with community partners to recognizing personal limitations to unburdening other researchers, but not all of these considerations will be relevant for every research setting nor will completing every one guarantee a project is ethically sound. As we think about ethics, we must also accept the nuance of ethics in research. It is hard to navigate a purely ethical path; mistakes are inevitable but doing nothing can be equally or even more harmful.

So, where do we go from here? We hope to highlight what makes engaging with marginalized people in research difficult, but also that it is important to not let these complexities prevent good research from being done. While we cannot solve the exploitative nature of research, we point out that the power that comes with being a researcher can be used for the promotion of others. However, when researchers overestimate the benefits of their work and underestimate the risks, this will inevitably lead to exploitation.

As we position these topics as tensions, one might ask that given all the potential for harm, why do research at all? It is important to highlight here that researchers are often motivated by the desire to help others or to give back to the world in some way. While we cannot ignore the real evils of how marginalized people have historically been included in research, researchers can and have had meaningful, direct impacts on society, attempting to counterbalance researcher’s inherent potential for harm. For example, increased research attention toward people historically left out of scholarship has led to improvement in various dimensions of many peoples’ lives. Bennett and Keyes pointed out that while assistive technology has not always been thoughtful of people with disabilities, they have also improved quality of life for many (Bennett & Keyes, 2019). Several research projects such as Kane et al.’s Slide Rule (Kane et al., 2008), Dimond et al.’s work on collective storytelling for a social movement (Dimond et al., 2013), and Dillahunt et al.’s efforts to help renters negotiate energy bills with their landlords (Dillahunt et al., 2010) have contributed to forward movement for different groups of marginalized people.

Reflecting on approaches to research is not an easy task. Doing so requires great awareness and, at times, willingness to admit that you have made a mistake, but we hope that readers continue to question their work to decide whether they are moving forward in the best, most equitable way possible. We hope that the future of HCI research that engages with marginalized people is one that builds and values relationships with communities, addresses inequities in how the field treats marginalized researchers, and positions itself as a space for progress rather than stagnation.

These lessons that highlight the importance of researcher reflexivity, undoing traditional exploitative practices, and allyship across all interactions in research provide a foundation that has influenced my analytical orientation, methodological decisions, and epistemologcal stance in future work. The impact of my own embrace of these four tensions has most manifested in Project OISET, a series of studies that work towards designing an online, interactive sex education tool for and with trans and queer youth, which I describe in Chapters 4 and 5.

Chapter 4. Designing an Online Sex Education Tool for Transgender and Queer Youth[8]

Project OISET involves a series of studies that work towards a broader goal of designing sex ed resources for and with trans and queer youth. With the lessons that I developed in the previous chapter in mind, I initially set out to investigate the foundational design needs of such a tool through qualitative engagements with trans and queer youth. Trans and queer youth have and are historically oppressed by systematic cisheteronormativity, capitalism, ageism, and classism. In addition, trans and queer people of color, disabled trans and queer people, and additional intersecting marginalized identities face further oppression through racism, ableism, and more. As such, I have taken up the previously depicted findings in this study by examining the design priorities of trans and queer youth through an intersectional and holistic lens. As I have learned—and continue to comprehend—trans and queer people have a unique perspective of marginalization particularly in the United States, warranting the need for a deep exploration into the exact contours of these experiences and analysis into how technology can support their ambitions.

While many students across the United States lack access to evidence-based sex education (Bleakley et al., 2006; Stanger-Hall & Hall, 2011), what *is* taught largely disregards the experiences of trans and queer youth (Elia & Eliason, 2010). Trans and queer individuals have different needs than their cis-gender peers and have previously characterized school-based sex education as inadequate and, at times, harmful (Haley et al., 2019). As a consequence of this lack of information, they are at higher risk of several negative health outcomes such as sexually

---

[8] This chapter was written in collaboration with Katie Albertson, Florence Williams, David Inwards-Breland, Sean A. Munson, Julie A. Kientz, and Kym Ahrens and was published in Interaction Design and Children 2020 (Liang et al., 2020).

transmitted infections (STIs) and experiencing violence in romantic and sexual relationships (Brennan et al., 2012; Griner et al., 2017; Reuter et al., 2017).

Building upon previous research on what information trans and queer youth seek in sex education, we sought to understand the format in which these youth prefer to receive sexual health information and to understand design considerations for a potential online, trans and queer specific sex education resource. In this study, we address the following research questions

> RQ4a: How can the design of an online interactive sex education tool support (or not support) trans and queer youth with their health needs?
>
> *RQ4b*: How do trans and queer youth prefer to receive sex education-related information?
>
> *RQ4c*: What role can design and technology play in developing effective sex education resources for trans and queer youth?
> *RQ4d*: How can we adapt current participatory design methods to gain insight into difficult-to-discuss topics like sexual health?

To address these questions, we engaged with 19 trans and queer youth in two focus groups, a three-week Asynchronous Remote Community (ARC) study, and a final co-design session to understand design requirements of an online sex education resource. Our research makes three contributions:

1. Identification of preferences for how trans and queer youth would like to receive different sexual health-related information,

2. Empirical findings for design needs for an online sex education resource for trans and queer youth, and
3. Novel methodological approaches that can be used to explore sensitive topics with teens, including a) a new “Four Corners” design exercise that builds on the line judging method (Walsh et al., 2013), and b) combining in-person focus groups with an online ARC study.

4.1 Related Work

4.1.1 Sexual Health Needs of trans and queer Youth

Trans and queer youth —people ages 12 to 21 years old whose sex assigned at birth does not accurately capture who they are— have unique sexual health needs (Olson-Kennedy et al., 2016). As others have noted, sexual health for trans and queer youth is more than just sexual behavior; it encompasses internal and social dynamics such as challenges with body image, sexual anatomy, gender dysphoria, disclosing gender to a partner, and communicating with a sexual and/or romantic partner (Olson-Kennedy et al., 2016).

Despite the clear need for tailored, gender-affirming sex education resources for trans and queer youth, only a few studies have explored the specific sexual health requirements of this group. In a 2019 study, Haley et al. revealed two key insights in regard to what sexual health information trans and queer youth look for and where they get such knowledge (Haley et al., 2019). First, they report that trans and non-binary youth commonly receive sexual health information from their schools, healthcare providers, peers, romantic partners, and online sources, but the first two sources are limited due to irrelevant curriculum and varying quality of interactions with providers (including experiences that can be ignorant or even harmful). Second, they surfaced eight sexual health content needs described by trans and queer youth: puberty-related gender dysphoria, non-medical gender-affirming interventions, medical gender-affirming interventions, consent and relationships, sex and desire, sexually transmitted infection prevention, fertility and contraception, and healthcare access (Haley et al., 2019).

To understand the changes happening in their bodies and how to navigate developing sexualities and their social implications, many trans and queer teens go online to find information (Fox & Ralston, 2016; Schimmel-Bristow & Ahrens, 2018). While some online resources can provide relevant information, many are often unvalidated, unmoderated, and some also spread misinformation (Haley et al., 2019). Online spaces are also useful testing grounds for many trans and queer youth, allowing them to explore their identities, seek information, and connect with others (Faulkner & Lannutti, 2016; Fox & Ralston, 2016; Gridley et al., 2016; Mitchell et al., 2014; Schimmel-Bristow et al., 2018). Given research demonstrating that trans and queer youth tend to use online spaces as resources, there is ample opportunity to identify the design needs of such technologies and specific ways trans and queer youth can digitally engage with sexual health topics.

4.1.2 Designing for and with Youth

Research with youth presents a unique set of challenges, such as access barriers and communication struggles, but focus groups have proven to be one method for effectively engaging with adolescents because they work to rebalance power dynamics, among other reasons (Poole & Peyton, 2013). As a result, Interaction Design for Children (IDC) research has taken up participatory and co-design methods (e.g., Pitt & Davis, 2017; Metatla & Cullen, 2018), with some researchers developing and adapting their own techniques. For example, Walsh et al. introduced Line Judging in which participants position themselves on a line drawn on the ground to reflect their positive or negative preferences for an idea or topic (Walsh et al., 2013). Line Judging allows participants to express opinions on a spectrum, spatially visualize their choices, and explain to researchers their rationale for choosing their positions. Additionally, Guha et al. presented the Mixing Ideas method for collaborative brainstorming (Guha et al., 2004). Mixing Ideas occurs in three stages: individual idea generation, sharing ideas in a small group, and sharing ideas with the whole group. This breakup into three steps helped individual participants express and share their ideas more freely.

These methods have been instrumental in developing insights into a wide array of topics such as identity formation (Coenraad et al., 2019) and cyberbullying interventions (Ashktorab & Vitak, 2016). Researchers have also used participatory design methods to engage with marginalized youth such as immigrant teens (Fisher et al., 2014), Syrian refugee youth (Fisher et al., 2016), and Latina teens (Vacca, 2019). Participatory design methods are particularly impactful for the ways they enrich the work and give youth a sense of belonging and empowerment through their participation (Ryan et al., 2013). These methods have proven useful in engaging with marginalized youth because they highlight voices and perspectives typically left out of research (Marcu et al., 2016). However, there is a large gap in addressing design needs for trans and queer youth both in IDC and Human-Computer Interaction more broadly; at the time of this study, there were no studies focusing on trans or trans and queer youth in the ACM Digital Library.

For studying people who are difficult to access, the Asynchronous Remote Communities (ARC) method is useful for studying and bringing together participants who might normally be separated by large geographical distances and might struggle to find community in their immediate areas, such as people with rare diseases (MacLeod et al., 2016) and people living with HIV (Maestre et al., 2018). ARC is well-suited to studying adolescents: given their preference for online interventions, it also makes sense to incorporate such preferences into research methods (Poole & Peyton, 2013). From the IDC community, Bhattacharya et al. used the ARC method to engage teens in designing new stress management tools (Bhattacharya et al., 2019).

4.1.3 Policies for Trans and Queer Youth

Within the US, there has been overall support for comprehensive sex education in schools, yet a 2016 report showed that only 38% of schools covered 19 critical sex education topics set by the Centers for Disease Control and Prevention (Brener et al., 2017). While conversations about the state of sex education in the US have historically forgotten about trans and queer youth, signs of change have begun to emerge. For instance, Healthy People 2020 Adolescent Health's AH-9 specifically addresses sexual orientation and/or gender identity-based harassment (Healthy People, 2020).

Policy is an important consideration alongside practice and design (Jackson et al., 2014). Policies, both governmental and private, can have tremendous influence on groups, such as trans and queer people, who face systematic prejudice. For example, several states have introduced bills restricting public school participation in interscholastic athletic events at which athletes of different biological genders are allowed to participate in competition against each other, unless the event specifically includes both biological genders (Cason, 2020). Such policies can limit the participation of and opportunities for trans youth in athletics, and they also further normalize discrimination.

In addition to government policies, platform policies can also result in promoting health of trans and queer individuals and discrimination. For example, Haimson et al. described Tumblr as a "trans technology" for the ways it allowed community building among trans users and information sharing. However, new policies in December 2018 banned "adult" content, which ended up erasing much trans-related content, thus removing an important resource for its trans users (Haimson et al., 2019). Policy implementations—whether they are governmental or from platforms—the everyday experiences of trans and queer youth, and designs must be considered alongside the policies that shape their use.

4.2 Methods

4.2.1 Recruitment

We employed maximum variation purposive sampling (Etikan et al., 2016) with the goal of recruiting a diverse sample with a wide variety of gender identities across the trans gender spectrum. We additionally sought out a range of youths' age to strike a balance of experiences with sexual health. Participants were recruited from Seattle Children's Gender Clinic and three community-based organizations in the Greater Seattle area that serve local trans and queer youth. The community organizations assisted the study team with recruitment by providing study information to youth, referring interested youth, or allowing research team staff to recruit directly during existing support groups and events.

4.2.2 Participants

A total of 19 youth participated in at least one session who ranged from 15 to 21 years old (M=17, stdev=2). Similar to a study by Ahrens et al., we included both current adolescents and young adults who are just beyond adolescence to allow for reflection on both concurrent and more retrospective effects of design considerations (Ahrens et al., 2016). Because of this age range, we hereafter refer to participants as youth. Of the participants, 5 identified as transgender female, 9 as transgender male, 5 as non-binary, 2 as gender fluid, 5 as male, 2 as female, and 1 as agender (the total exceeds 19 because some participants have more than one gender identity). Our demographics survey mistakenly conflated gender and sex and should have allowed participants to identify with a gender rather than a sex (e.g., trans woman instead of trans female).

4.2.3 Initial Focus Groups

During the first phase of the research study, members of the research team facilitated two initial focus groups (n=7 and n=12). Each focus group occurred in-person, prior to the COVID-19 pandemic, and lasted approximately two hours. The study team obtained written consent prior to each focus group and youth were asked to complete a brief survey consisting of questions about demographics and their current sources for sexual health information. After reviewing the objective of the research study, the study team used a semi-structured focus group script to facilitate discussion around the youths' conceptions of sexual health and how they access sexual health information. Please see Appendix A for the full protocol and prompts. The focus group sessions were video recorded with participant consent.

Following the semi-structured interview script, we employed a new participatory design technique called the Four Corners Exercise, which builds upon the line judging technique (Walsh et at., 2013). Four Corners adds an additional dimension to Line Judging as well as allows participants to make different kinds of decisions (i.e., preferences among choices rather than positive versus negative reactions). Also similar to Line Judging, Four Corners generates insight into the youth's preferences as they share their reasoning for choosing a specific position and, if relevant, why they chose to move.

In this exercise, researchers labeled each corner of the room with different modes of receiving sexual health information: in-person, written, question and answer (Q&A), and videos, with the understanding that aspects of these formats may overlap or co-exist. These formats or methods of delivering sexual health information were decided upon by the research team prior to the focus groups based on an extensive exploration of existing sexual health resources and prior qualitative work (Haley et al., 2019). We defined each category as follows: written (information that is read, online articles or fact sheets, pamphlets, or written articles or factsheets), in-person (1-on-1 interaction, doctor or provider visit, talking with partner, teacher presenting curriculum, or phone hotline), Q&A (text chat, FAQ format curated by resource creator or doctor, ask-me-anything format, panel with experts or lived trans and queer experience), and video (YouTube, other video platforms, videos embedded in articles, or film/TV). Participants were also instructed that they could remain in the middle of the room if they felt that none of the corners represented their format preference.

The research team generated a list of content area requirements based on a prior qualitative study with trans and queer youth (Haley et al., 2019). The topic areas included: 1) STI prevention, 2) fertility and contraception, 3) puberty and dysphoria, 4) sex and desire, 5) relationships (consent, boundaries, and disclosure). In the first focus group, we asked the youth to place themselves in a position in relation to the four formats that reflected their preferences for receiving information on each sexual health-related topic. In the second group, we iterated on our protocol by providing a hypothetical scenario for each sexual health topic and asked that they place themselves in response to that scenario to better help ground the discussion around sexual health.

The Four Corners exercise provided a way for the youth to express multiple preferences; for instance, some went directly to a particular corner while others positioned themselves in between two or more corners. Additionally, once all youth had chosen a spot to reflect their preferences, we asked each person to explain their reasoning. Why did they choose this particular spot? As each individual gave their opinion, some of the others would move too. The Four Corners exercise allowed the research team insight into rationale for the youth’s preferences not only from their initial positions in the room but also from where and why they moved. The youth’s positions were documented after discussion and we formed “heat maps” indicative of participant preferences. Heat maps were then summarized and converted into

Table 6. Focus groups were video-recorded, and notes were taken during the focus group sessions by study personnel.

4.2.4 ARC Prompts

Focus group participants were offered the option to participate in a follow-up Asynchronous Remote Communities (ARC) group on Discord[9] for 1 month following the focus groups. Previous ARC studies have used Facebook (MacLeod et al., 2016) and Slack (Bhattacharya et al., 2019), but we used Discord because it similarly allows for communication in private online channels and because of its popularity among this age group and among trans and queer youth. We set up separate "servers" for each focus group cohort, and there were 6 youths in the first group and 10 in the second. We asked participants to work on a weekly activity for three weeks, and we estimated each would take 20 minutes to finish. Participants were givsysen $10 per weekly activity.

We designed a mix of divergent and convergent thinking prompts to either generate new ideas or choose and refine existing ideas respectively. Convergent and divergent thinking strategies are both necessary for creative thinking and for socially meaningful solutions (Woodman et al., 1993), and thus we included activities that worked in both forms. Appendix A includes further details about each activity. The three activities were:

1. Posting drawings or descriptions of their ideal sexual health resources, with or without the use of technology (divergent thinking prompt),
2. Evaluating three existing sexual health or health resources chosen by the study team because of their representation of a variety of formats and designs: Transgender Teen Survival Guide Tumblr, the Clue Sex Blog, and they2ze (convergent thinking prompt), and

---

[9] https://discordapp.com

3. Designing their ideas for a technology-based sexual health resource (prompts included both divergent and convergent thinking components).

4.2.5 Co-Design Session

Approximately 6 weeks after the final ARC group concluded, the authors met with 4 participants who had also been involved with the focus groups and ARC study for an in-person co-design session of an online sexual health platform. All previous focus group participants were invited, but we sought a smaller group, and thus the design session was held once we had a sufficient number of participants, representing a diversity of gender identities, enrolled. The co-design session was video recorded with participant consent. Using the Mixing Ideas method (Guha et al., 2004), participants first sketched wireframes individually. Afterward, they paired up to share their sketches and ideas and develop a joint design together. Finally, each pair worked together, shared their designs, and created a final prototype. The goal of this co-design session was to a) create wireframes of an online sexual health resource for trans and queer youth and b) understand design rationale for each component of their resources. Appendix B presents wireframes from our co-design session.

4.2.6 Data Analysis

We conducted a thematic analysis (Braun & Clarke, 2006) of transcribed video data from the focus groups and co-design session, the text and design data pulled from the Discord groups, and the wireframes created in the co-design session. To build on focus group results during the ARC, we accelerated focus group analysis by using a modified transcription process. Two members of the research team noted key themes from each 5-minute increment in the group videos. They transcribed quotes around key discussion points (such as the summary of a discussion around preferred format for a specific content area) on a templated note-taking document and discussed when disagreements occurred. An initial codebook of themes was created a priori based on the key goals of the study. Three authors reviewed and coded the focus group transcripts and ARC postings for key themes, iterating on codes and resolving disagreements via discussion. We developed codes generally around format, content, and design preferences. Finally, two investigators re-read all notes, code summaries, and primary data sources and re-summarized main themes in memo form. We compared all memos generated to iterate upon emergent themes.

The research team confirmed themes and analysis of their data with the participants throughout the study, once during the ARC portion and again during the co-design session. At those points, the research team generated and presented interim summaries of participant ideas and requirements and asked participants for feedback and clarifications. This allowed us to ensure that we were not misinterpreting data and helped ground our analysis.

Considering the four tensions outlined in Chapter 3, my entanglements with my shared membership affected the analysis of our engagements with trans and queer youth in this study. As I reflected on my own queer identity, I made careful methodological choices so that participants felt as comfortable as possible as we discussed their sexual health information preferences. For instance, I scoped out whether our study space had gender-neutral bathrooms, conveyed through my clothing and appearance that I was queer myself, and conscientious about protecting and deleting personally identifiable data after we finished data analysis.

4.2.7 Ethical Considerations

The research team prioritized creating a gender-affirming, safe environment. Study staff used youth's chosen names (as opposed to legal names) and their pronouns. Focus groups were conducted in a private room where many participants attended support groups for trans and queer youth. Due to the vulnerable nature of this population, we created protocols in the event that a youth expressed emotional distress or thoughts of harm to self or others. For full protocol for disclosure of self-harm, please see Appendix C. The research team moderated ARC discussion threads and encouraged the youth to create anonymous usernames that protected their privacy. At least one member of the research team monitored online discussions daily for concerns of safety or emotional distress, though no such posts occurred. To protect privacy, the research team pulled data from each Discord group, anonymized content, then deleted each server at the conclusion of the study. Finally, all sessions and protocols were approved by Seattle Children's Institutional Review Board.

4.3 Results

In this section, we present themes in three main categories: 1) preferred formats and sources, 2) design needs of trans and queer youth, and 3) other considerations beyond sexual health.

4.3.1 Preferred Formats and Sources

	Written Material	Q&A	In-Person	Video	Indeterminate/ Middle
Sexually Transmitted Infections	11	5	5	0	2
Contraception and Fertility	6	3	8	4	4
Sex and Desire	5	1	11	3	5
Puberty and Dysphoria	1	5	8	4	5
Consent, Disclosure, and Other Relationship Topics	3	6	9	6	2

Table 6. Final Format Preferences Based on the Four Corners Exercise

Preferred formats for receiving information varied by the type of information. For each previously identified content area, we tracked the relative preferences for the four format options given in the Four Corners exercise (see Table 6). If a participant finished the exercise between two or more categories, they were counted as preferring both categories. If a participant expressed that multiple formats would be acceptable but did not identify specific preferences, they were placed in the indeterminate/middle category. In Table 6, we note that although contraception and fertility were combined when we presented the topics, participants tended to describe a preference for written basic information on contraception and in person for discussions about fertility. Additionally, if a participant described multiple preferred formats for a specific content area, they were counted in all preferred categories (i.e., categories are not mutually exclusive). If a participant expressed that multiple formats would be acceptable but did not indicate specific preferences, or did not describe a specific preference, they were placed in the indeterminate/middle category.

Participants expressed that their format preferences depended on the type of information they were seeking. They highlighted three themes of information types: 1) universal, fact-based sexual health content (i.e., information about STIs and contraception) and 2) content that requires personalization to an individual's specific gender and/or medical transition, and 3) relational topics (e.g., consent, disclosure of gender). Additionally, the source of information is also an important consideration regardless of format.

Fact-Based Sexual Health Information

The majority of participants preferred a written format for receiving universal, fact-based information on STIs or contraception. Participants expressed that written formats, including print and online text, are useful for having an initial base of knowledge they could refer back to at any time. Some participants also said written information allowed for discrete access to information, which was helpful to avoid social anxiety. One participant from Focus Group 2 expressed: *"I think written information is really good [...] because it eliminates a lot of the shame because it's hard to get up and find someone and be like, hey, can I just talk to you about a sex* *question? And it's also something you have access to if it's online, at all times. It's really useful."* Further, no consistent preference was expressed for paper versus online written information or vice versa.

Some participants expressed the value of receiving information via an in-person interaction, particularly with medical providers. In Focus Group 1, one perceived benefit of having an in-person discussion with providers that emerged was the idea that STI testing or contraception could be immediately integrated into the visit if desired by the participant. Other participants expressed that having in-person conversations could be de-stigmatizing. Another youth said they would prefer the online Q&A format for STI and contraception information because it would allow them to gather multiple perspectives and build an online social community.

Some participants expressed reservations about in-person or Q&A formats. Reasons given included social anxiety, a lack of anonymity, and potential for stigmatizing responses if a provider or facilitator responded in a non-affirming way. An additional concern related to Q&A format was that, without moderation by experts, answers could potentially be posted by sources that did not have accurate information or were speaking only from anecdotal experience.

Finally, after a discussion about the relative merits of each of these formats, participants in both focus groups reached a consensus that a combination of formats might increase accessibility for youth. Specifically, youth most often suggested a combination of written with in-person or Q&A, as this would facilitate reading the information beforehand and/or referring back to it easily afterwards. A participant from Focus Group 1 stated, *"birth control is such a specific thing that eventually you will need to talk to your doctor, but written [information] is a good place to start."* Adding to this, a participant during Focus Group 2 expressed: *"if I had a conversation in person…and they give a whole bunch of different information and I remember very little or none of it. But if I had it written down then it is like, this is the thing…does that make sense?"* Another participant from Focus Group 2 explained their split decision and placement during the Four Corners Exercise: *"I'm mostly standing down the center because…I know a lot of people who only tend to retain memory through writing and people who retain through experience."*

Sexual Health Topics Requiring Personalized Information

Participant preferences changed when it came to sexual health topics that called for information to be more personalized to each individual's experience or transition. For these content areas, youth in this study preferred in-person, Q&A, and, to a lesser extent, video formats over written information. Some participants again recommended offering the information in multiple or integrated formats to accommodate those with different learning styles, social anxiety, or those who were not yet ready to come out.

When discussing specific STI treatments or contraception options, many participants preferred in-person or interactive discussions, as they felt that this method afforded them the ability to receive information tailored to their specific needs, gender, medications/treatments, and/or behaviors in which they were engaging. Some preferred to get information in-person specifically from a gender-affirming provider or via an interactive Q&A format moderated by an expert because it would allow them to pose personalized questions that could not be included in a written article or fact sheet. As a participant wrote during the ARC, *"I think everyone can see the benefit of having this information literally coming out of a certified person's mouth. Specifically, someone who may or may be a doctor/nurse but who is trained in medicine when it comes to preconception along with birth control and menstruation."*

Similarly, when learning about the effects of gender-affirming treatments on fertility, sex, desire, and dysphoria, participants emphasized in-person or Q&A formats for personalizing information to a person's specific needs, particularly with regard to effects of hormone therapy. As one participant from Focus Group 2 stated, *"everyone's puberty is different and everybody's transition* *is different so that's why Q&A can be helpful."* Similarly, another participant from Focus Group 1 said, *"when you start hormones, you're kind of going through that 2nd puberty…there's a lot of stuff online, generally puberty is different from person to person and it can't really be generalized…it's not something everyone can feel the same about, especially with dysphoria."*

Relationship-Oriented Topics

When approaching relational topics such as navigating consent with a partner, setting and maintaining boundaries with partners, and deciding when and how to disclose transgender and/or trans and queer status to a prospective partner, participants expressed a desire for formats that provided youth with scripting for how to handle fluid situations, allowing them to observe body language, facial expressions, tone of voice, and specific language. Thus, participants primarily preferred both in-person and video formats for these topics. A participant from Focus Group 1 weighed the pros and cons of in-person versus videos: *"Doing stuff in person always prevents misunderstandings, which I've had my fair share of, and it's definitely a lot easier to get your point across. But also videos are really good for learning how to go about bringing up the topic, whether you are asking someone about their identity or coming out about your own identity."* Another participant from Focus Group 1 debated the same question: *"With videos when you see someone talking about their own experiences you can see more how they feel… you can relate more and it also emphasizes the importance when they talk about stuff that they've experienced."*

Preferences for Information Sources

In considering the source of fact-based information, participants almost universally stated that they preferred that content be developed by a medical provider with experience in gender affirming care. One youth from the second ARC group wrote about the limitations of Q&A or the lived experience: *"For the most part, I am all in support of the 'made by trans people, for trans* *people' idea. But I think some of this information would also be helpful if it came directly, not only from a trans person, but perhaps a therapist or a doctor who have worked with trans people and their experiences."*

Similar to general, fact-based information, participants tended to prefer to receive personalized information from a medical provider with expertise in gender care and knowledge of their specific treatments and desired treatment outcomes. One participant from Focus Group 1 elaborated: *"having in-person a doctor saying 'this is completely normal,' things like that because some people don't know how to relieve all of their sexual tension because as a trans person it's kind of hard to do that when you don't have all the resources to learn about how to do that."* Video or written materials were seen as beneficial by a minority of participants for tailored information. One participant from Focus Group 2 described receiving detailed written information at a conference for gender diverse people and said that that *"written material helped me understand that there are ways I can fix how I'm feeling, and there are ways that I can feel better about, and I've been pretty happy since then."* However, it was also described by some as impersonal and potentially harmful to those who may be undergoing transitions or journeys that do not fit what static materials might describe.

For relational topics, there was an emphasis by youth on the lived experience: participants expressed a desire for content to be created by transgender and/or trans and queer people. As a participant from the first ARC group noted, *"I think it might be good to show (in addition to the info regarding sex, std, puberty, etc.) LGBTQ+ video creators. Many who do content that I've watched go into some part of their stories on the info mentioned."*

In design practice, participants discussed how clarity of an information's source is important, and they shared that they view citations, author profiles, date published, and links to external resources to establish credibility. While reviewing an existing resource, one participant in the co-design session appreciated the sources: *“the citations support their reliability and accuracy.”* Another participant from Focus Group 2 conveyed that *“when you don’t get information from a really trustworthy source it can be really easy to believe something for many years that turns out to be absolutely not true…false information…a lot, a lot of misinformation.”*

4.3.2 Design Needs of Gender Diverse Youth

Discreet and Non-Triggering

While many of the youth recognized the value in having a trans-specific information resource, they also emphasized the importance that it be discreet over concerns that it might out someone if accessed publicly. Many focused on the logo and landing pages in particular. For instance, a participant from the co-design session suggested a more generic logo rather than one displaying a logo or symbol associated with the transgender community. Another co-design participant suggested a logo that could be recognizable within the community, but not obvious to others. They pointed out that the use of male/female symbols and colors from the trans flag (white, pink, and blue) could immediately out a person. The co-design participants agreed that whatever color the trans-friendly resource used, that it should not immediately be obvious that it is meant for trans users yet is easily identifiable by community members.

Many participants advocated for the use of visuals for an online sex education resource but warned that some content might be triggering to some users. Participants discussed the importance of presenting non-triggering information and visuals as a part of an online sex education resource. Some participants debated the use of cartoon images for things like anatomy, as some sex educational resources have used, versus real ones. They suggested two possible features for this: hideability of visuals and blacklisting of topics. In the first Discord group, a participant wrote *“on the actual website, I think there should be some pictures, but that are not actively visible to prevent discomfort (i.e., a picture of a uterus).”* From the same group, one wrote *“I’d like more emphasis on images too, but the images should be hidden under a ‘spoiler’ system. This is to prevent triggering.”* In our co-design session, a participant introduced a feature where visual content would be hidden by default, obscuring potentially triggering visual content where the person could click to show or hide content.

Participants came to a general consensus around the ability to blacklist or mute tags (i.e., controlling what content they see). In the co-design session, one participant designed the blacklisting feature, pointing out that articles and resources on the site should have tags that described the larger topics covered, which would make it easier to find relevant information and, crucially, obscure anything that might be triggering to a person. A participant from the second Discord group wrote *“[I]'d really like that idea to feature blacklisted informational tags as well, assuming there's an account registration alongside this feature to also save worthwhile articles. basically, to hit all bases in removing and avoiding certain topics as much as it helps search and gather information.”* Some participants also asked for an additional feature that involved personalizing the resource through quizzes. The co-design session participants voiced a need for a “*triggers quiz & types of info interested in to tailor results” or a “short quiz or bio to filter out triggering information*.”

The Importance of Incorporating Lived Experience

Participants emphasized the importance of both incorporating lived experience perspectives that represented different viewpoints, and of making it prominent on the website that content was at least partially written by trans and queer persons. For instance, one participant from the first Discord group said, *“I think it's really important to have multiple experiences shared by non-binary people, especially of all ages. I feel like society has been telling non-binary people that their identities are just phases, so they don't really have an idea of what they will look like when they're older. It's a wise idea to have an older non-binary person who can say, ‘Hey, I did it. And I'm still* *non-binary.'"* From the same session, another mentioned that people who might engage in hormone therapy might start it at different times, thus making second puberty difficult to generalize. Additionally, a participant from the second Discord group talked about how *"it's useful to have resources sorted by if they are more aimed at transfem people vs transmasc people, because it can help with people who don't know what terms mean."*

Building Credibility through Security and Relevance

Many youths wished for a sex education resource to be professional, which carried a range of definitions. For some, a professional site meant that it was credible and certain information was linked to trustworthy sources (e.g., medical journals). Participants from Focus Group 1 also expressed the difficulty of assessing whether information they came across online was credible or not. Some participants referenced sites created by TERFs (Trans Exclusionary Radical Feminists) that initially come across as well-intentioned but, after closer review, actually spread misinformation and harmfully encouraged dysphoria.

Data privacy and security was another significant theme that participants brought up in considering an online sex education resource. As one participant from the second Discord group wrote, *"[l]egally, confidentiality should be the topmost priority for a sensitive topic such as sexual health."* Some thought it was important for such a resource to be transparent about who is publishing the resource, whether cookies are being used, and how data are tracked (or not tracked). Many participants strongly suggested that their ideal resource would not track their data.

Relatedly, there were discussions around how to integrate a safe and secure, yet optional, log-in system. As some co-design participants discussed, logins could allow for personalized trigger warnings, as mentioned in the non-triggering section, and for saving articles to reference later. However, others pointed out that accessing information while using an account also could mean that their data might be tracked. Youth also noted that accounts and logins could be anonymous (usernames or auto-generated, such as a number and a color) and that people should not be forced to use their real names.

To improve relevance, participants highlighted the need for orientation towards local resources, and this theme was particularly salient when participants during the ARC were asked to review existing resources. From the second Discord group, one youth pointed out *"I'd also like to be able to specify search by network (like if I want to stay within the Seattle Children's Clinic as much as possible, I can contain my search results to there first) or within a zip code or city limit."* Another from the same server wrote, *"I think having a mobile app serving as a link between youth and provider is an innovative and reliable technique. with more and more trans and queer youth scouring the internet for answers safe places, where else would be a better resource than the one sitting in your pocket? it feels like a google maps for the transgender community, and that's really comforting."* In the co-design session, participants highlighted the inclusion of "*location-based info*" and even drew out a map that would display local medical teams, doctors, and other resources.

A few participants made it clear that having poorly updated information about local resources would be worse than having no local resources section. For example, They2ze, a youth-designed app with a database of health and life resources vetted by the trans community, drew criticism for not being updated, as one participant wrote *"they2ze has so much potential, it is unbearably disappointing that the last time it was updated was two years ago."*

4.3.3 Other Considerations Beyond Sexual Health

Although activities focused on sexual health, participants consistently brought up several related themes. First, they talked about other aspects pertaining to their health, such as their hormone levels, side effects, expected pace of physical changes, interactions with birth control and other medications, and mental health resources. For instance, a participant from the first Discord group wrote, “*I feel a scientific and medical help section would be great and help people understand the health side of being trans*.”

Several participants also described non-sexual/reproductive health situations in which they had to deal with coming out and/or answering questions about their gender. A participant from Focus Group 1 expressed: *“I go to the same school I’ve gone to my entire life, so for the most part I don’t have to deal with [coming out]. But also, when I get out and I’m ‘stealth’ I feel like I’m alive for the first time, but then I don’t want to tell anyone anything so I’m terrified. I’m living but I am terrified.”* Additionally, participants emphasized that basic information, such as etiquette for how to treat a trans person with respect, needed to be taught to everyone regardless of gender identity to reduce stigma and dysphoria.

Our design sessions also surfaced aspects of designing for better sexual health distinct from technological solutions. Particularly, the participants called for a redesign of sexual health curriculum to include trans and queer topics. When discussing their own experiences with sex education in formal, American educational settings, participants revealed several failings. For instance, curriculum might treat sexual health as a taboo subject by either excluding the topic altogether or shallowly covering it. As one Focus Group 2 participant expressed: *“My school has history of treating gender in sex education like poison oak, you will touch it and then never touch it again.”* A youth from Focus Group 1 called out that *“schools have created ignorance around trans people by not talking about their issues; there should be education for everyone on trans issues and trans etiquette.”* Neglecting these topics can have adverse developmental effects. One participant from Focus Group 1 shared that they transitioned later than they preferred to because information on their identity was not available through their sex education.

4.3.4 Reflection on Method

Although combining in-person methods with the ARC is counter-intuitive for an ARC and not possible in many cases, we found there were benefits to doing so. For example, after our second focus group concluded, many participants had congregated to one corner of the room next to the table of food. We were pleasantly surprised to find that they were sharing their Discord usernames and connecting with each other online without having been prompted to do so. One exclaimed that they had never been in a room of other trans and trans and queer youth before. The Discord server consisting of participants from the second focus group had many interactions. Participants built on each other's ideas and had debates, appearing to have established trust and rapport perhaps in part due to the connections they made from meeting in-person. However, we did not conduct a network analysis, nor did we interview participants to reflect on our methods, so we cannot make definitive claims about the effect of this combination.

The Four Corners Exercise that we introduced is just a slight modification to Walsh et al.'s line judging technique (Walsh et al., 2013), but adding an additional dimension for participants to choose from led to added insight into the nuances of their preferences. Having an expanded range of options allowed the research team to identify the situational nature of the questions we were posing, as outlined in our findings. Additionally, the process of having each youth share their rationale for their placement, then watching others move based on this reasoning and in turn express why they moved, generated valuable feedback.

4.4 Discussion

Our results inform design choices about the formats and sources for sex education resources for trans and queer youth (RQ4a), as well as the role of design and technology in the creation of those resources (RQ4b). While our research focused on design, the results also point to policy implications of equal importance to those for design, and we discuss those as well. Finally, our results inform future research, particularly participatory research addressing difficult-to-discuss topics like sexual health (RQ4c).

4.4.1 Implications for Design of Sex education Resources for Trans and Queer Youth

Designers of a sex education resource for trans and gender diverse youth should consider 1) which formats and sources to present information and 2) two themes that cut across the design needs described above, considering safety and the range of trans and queer experiences.

The participants of our study preferred certain formats based on the nature of a specific sexual health topic. They favored written content or reference materials from a credible source for fact-based information and interactive and/or multimedia approaches for more relational content. Thus, a hybrid of in-person and online content may be the best strategy for designing resources to serve trans and queer youth as they navigate a multiplicity of experiences. Additionally, bringing together interactive, online Q&A with either a gender specialist provider or person with lived experience with written and video resources might allow for broader reach to more disenfranchised youth. This would help reach those who would not normally have access to in-person sex education resources due to a lack of parental support, logistical or geographic limitations, or access to gender-specific care (Gridley et al., 2016). Finally, sexual health information is intimately linked with other aspects of the trans and queer experience, thus effective sex education resources will likely include content addressing other aspects of trans health, such as transition, hormones, or pubertal blockers. This may also increase the appeal of the resource to trans and queer individuals, as well as make it less stigmatizing or embarrassing to access content.

Our results suggest that technology can play an important role in the sex education of trans and queer youth, including both physical and social development. An online resource has the potential to provide important information that may help individuals form their identities faster or seek help when necessary. However, designers of such an online tool should consider two design implications salient across the design needs raised in our findings: designing for safety and designing for inclusion.

Considering safety should involve protecting youths from emotional distress by avoiding triggering dysphoria and from others who might try to harm them by not outing users to the public and securing their data. Youth in this study created ways to account for each such as blacklisting and toggling hideability features, employing discreet design, and non-mandatory login capabilities. The option to have privacy and anonymity and the ability to block out dysphoria-producing content is paramount for this group; if resources are not designed with care, they could inadvertently contribute to dysphoria or stigma for this population. More recently, researchers have emphasized safety for online trans and queer users as a design priority (Haimson et al., 2020). Scheuerman et al. called for technology designers to attend to subtle forms of violence perpetrated online in addition to prominent ones (Scheuerman et al., 2018). In addition to Scheuerman et al.'s "insider harm" (Scheuerman et al., 2018), or harm from within an individual's social networks, designers should also consider harms that are experienced internally such as dysphoria, triggering content, or social comparison. In regard to data privacy, some have offered solutions such as allowing internet users under 18 to opt-in to data tracking and stronger mechanisms to erase youth's personal information (Smith, 2013). In our extension of these ideas, we also draw from Pinter et al.'s call for giving youth more agency in their data privacy and security. We recommend that technology designers consider this by being transparent about their privacy policies and letting youth choose what happens with their data.

Designers should also account for the range in developmental and social experiences of trans and queer youth. Designing for inclusion requires designers to recognize that even within the category of trans and queer youth, individuals encounter very different experiences on very different timelines. For instance, two youths of the same age may respond to hormone therapy differently or may take different doses or combinations of medications. Accounting for such variety is not an easy task, but it is important not to frame any one experience as a norm to avoid unnecessary and potentially harmful comparisons. Additionally, designers should consider that potential users may also have a spectrum of access to resources. An online tool can help extend access to care, but it is crucial that such a resource does not solely center the urban experience (Hardy & Vargas, 2019). Finally, if technology designers provide local resources for their users, it is crucial to regularly update such a database so that it is relevant and usable. As participants' reactions to they2ze demonstrate, it may be better to have no resource than an outdated one.

4.4.2 Implications for Policy

IDC researchers are faced with the difficult challenge of bringing youth online while also protecting them from potential danger. As such, IDC research needs to continue to expand its understanding of how we can shape future policy. Examining how policy and design are entangled is especially important in the context of this study, because online resources will have limited utility if current education policies prevent them from reaching the youths who need their content most. Therefore, technology designers cannot take on this problem space alone; they must advocate for policy that guarantees access to education content and resources for all youth.

Youths in this study highlighted structural changes that technology design cannot accomplish on its own. In conceptualizing an ideal sex education resource, many brainstormed solutions beyond artifact design and emphasized that education cannot ignore the experiences of trans and queer youth. Several in this study asked for inclusion of content about gender-diversity in sex education curricula for *all youth* as well as a way to address discrimination and ignorance. Policymakers should consider how to incorporate content that covers trans and queer experiences (i.e., definitions, basic etiquette for addressing a person who identifies as transgender, non-binary, or elsewhere on the gender diversity spectrum) into curriculum. Curricula should also take advantage of multiple modes of conveying certain kinds of information. In addition to school policy, we highlight participants' concerns over data privacy to push policymakers to modernize their conceptions of data (e.g., personal health data from wearables) and how to more effectively protect them. Finally, we challenge social media platforms to reconsider what counts as "adult" content when choosing what to ban. Algorithms need to be refined so that they do not alienate trans and queer users and the educational experience that their platforms can provide. Likewise, schools may need to consider whether content filters in place on school computers may inadvertently exclude youths from accessing necessary health content.

4.4.3 Implications for Research

Being able to collaborate with trans and queer youths on a resource for trans and queer youths was a valuable and rewarding opportunity, and so we reflect on the benefits and limitations of our methods and possible future directions. Participatory design proved effective for engaging with this group. As previous scholars have detailed, participatory design can help youth analyze and enact their identities through design (Coenraad et al., 2019) and surface and address systemic change (Booker & Goldman, 2016). Booker and Goldman additionally note that participatory design research is strengthened in the ways it allows for open dialogue and challenges traditional researcher/participant roles and who counts as learners versus who counts as an authority (Booker & Goldman, 2016). Our approach in this study embraced these principles as we made clear that the learning process and space was one that was co-created by researchers and participants alike. Doing so allowed for honest dialogues about traditionally difficult-to-discuss topics like sex education, sexual health, and their respective lived experiences. Previous research to understand how youth cope with and talk about other difficult and sometimes vulnerable experiences has yielded similar results. For example, Hong et al. also explored the need for an outlet to discuss a sensitive topic like managing a complex chronic illness as an adolescent (Hong et al., 2016), and we extend their findings by providing additional methods.

This study identifies individual support through the use of an online resource, and so future work might consider examining how to integrate social support into sex education. Additionally, other work might consider how to provide sex education through multiple channels, rather than through a singular, trans and queer-specific resource. Next, this study is rooted in Western, hegemonic views of what it means to be transgender and/or trans and queer, and we note that our findings merely represent a part of the trans experience. The participants of our study tended to consist of youth located close to urban areas with access to gender-affirming care or support, making our results difficult to transfer to all gender diverse youth. Finally, the size of our samples in each part of the study and the age range of participants might have concealed more specific needs than those surfaced in this study.

4.5 Relation to Dissertation

Trans and gender diverse youths deserve access to thorough and affirming sex education. Given the absence of sex education that encompasses the trans and queer experience, the online world has great potential in providing support to many trans and queer youth. We imagine our results inspiring the creation of an ecosystem of integrated resources, with coherent links among them, that are designed for privacy, safety, and inclusion. Designing such resources will not be enough, however, so we also discuss policy needs to promote access to those resources and gender-inclusive sex education. We also hope that researchers working with marginalized youth or studying difficult topics can benefit from our description of the Four Corners Exercise and our successes combining in-person focus groups with an ARC study.

Chapter 5. Understanding the Privacy and Security Needs of an OISET for Trans and Queer Youth

As participants in the initial design needs assessment study pointed out, designers of an online sex education tool for trans and queer youth must prioritize privacy and security. Thus, I set out to understand these needs more in-depth and how they overlap and intersect with the previously identified design needs.

Against the backdrop of this work and as of March 2022, there has been recent legislation that has been either introduced or passed that threatens trans young people's access to gender-affirming care and, more generally, their ability to grow and develop on their own. This rise in anti-trans legislation accentuates the need to protect young people's privacy and security. As of March 2022, the Idaho house of representatives has passed a bill that would "criminalize gender-affirming medical procedures for transgender youth and make it a felony punishable by life imprisonment for anyone who helps a child travel across state lines to gender-affirming healthcare" (Yang, 2022). Idaho's house of representatives are not alone in these efforts either. 22 states have introduced bills to "ban best practice medical care for transgender young people " in 2021 alone (Movement Advancement Project, 2021). In the face of such legislation, this study explores the role that design can play in countering these oppressive limitations so that trans and queer youth can live happily and be free to be themselves.

Data privacy is focused on ensuring that a user has control over and access to their personal information while security focuses on protecting data from external, malicious threats. To explore how social and technical dimensions of privacy and security come together for trans young people, I explored the following research questions:

> RQ 5a: What are existing threats that trans and non binary youth face today? What constraints exist that limit our abilities to intervene? What are current mitigation strategies that people use to address these threats and constraints?
>
> RQ 5b: What current design patterns for trans/queer technologies exist that protect privacy and security?

To explore these research questions, I engaged with people who work at or volunteer at organizations that provide social support, legal services, and health-related services to trans youth. First, I led a series of three focus groups with 16 people, followed by 7 more in-depth, semi-structured, and qualitative interviews. Qualitative data revealed how privacy and security play out in the context of participants' work experiences. I describe how participants account for the privacy and security needs of trans and queer youth in their own work practices. We then analyze these practices to suggest considerations and potential techniques for the design of online sex ed resources for trans and queer youth. Discussions led us to identify existing threats to the online privacy and security of trans and queer youth and better understand how to enact privacy and security protections in various design practices including account creation, default privacy settings, and the minimum necessary information to access the resource's features. In addition, these findings were then validated and further explored with members of a community advisory board, known as the Queer Trans Advisory Board, through online focus groups.

As a result, this work makes two high-level contributions. First, I advance a greater understanding of the current privacy and security practices and the privacy and security needs for an online sex education resource for trans and queer youth. By co-developing a threat model consisting of existing threats, constraints, and mitigation strategies, I additionally outline the landscape of privacy and security in this context for future designers and privacy researchers. Next, I propose a queer approach to the privacy-by-design framework that is better tailored to the needs and priorities found in the context of an online sex ed resource for trans and queer youth. By revealing gaps left behind by a more general privacy-by-design framework, I demonstrate how researchers can better situate this approach within contexts of marginalization and technology design. These findings are meant to guide two distinct audiences. First, privacy and security researchers can take away lessons developed around participatory threat-modeling and adapting the privacy-by-design framework into specific contexts. Next, health-focused researchers can also apply this privacy and security orientation into the development of health technologies.

5.2 Related Work

This research builds upon bodies of work related to the privacy-by-design framework and privacy and security research in HCI.

5.2.1 Privacy by Design Framework

The privacy-by-design (PbD) framework guides systems designers to account for privacy and security concerns throughout the design process, as opposed to an afterthought (Cavoukian, 2013). PbD consists of seven principles, shown in Table 7. Previous work has uncovered challenges to putting PbD in practice such as the difficulty to design for trust, privacy laws and regulations, financial costs, and more (Alkhatib et al., 2020; Stark et. al., 2016). This study, however, questions how the existing PbD framework aligns with queer-specific privacy needs.

1	Proactive not Reactive; Preventative not Remedial — anticipating and preventing privacy invasive events before they happen.
2	Privacy as the Default Setting — privacy is protected without the individual having to take action. It is automatically protected.
3	Privacy Embedded into Design — privacy is an essential part of the tool's functionality, not an add-on
4	Full Functionality — Positive-Sum, not Zero-Sum — avoiding false dichotomies in decision making. It is not privacy vs. security; we can have both.
5	End-to-End Security — Full Lifecycle Protection — security measures are put in place, from when data are collected, retained, and destroyed, from start to finish.
6	Visibility and Transparency — Keep it Open — assuring people involved that we are held to our promises and can independently verify if needed.
7	Respect for User Privacy — Keep it User-Centric — "to keep the interests of the individual uppermost by offering such measures as strong privacy defaults, appropriate notice, and empowering user-friendly options.

Table 7. Privacy-by-Design Principles

Privacy-by-design is gaining traction in HCI, especially when considering the technological needs of marginalized people. Wong & Mulligan specifically call for the integration of HCI methods, like participatory design and speculative and critical design, to develop a "sociotechnical stance on privacy" (Wong & Mulligan, 2019). As they write, "design thus is not just a tool for solving privacy problems, but also a tool to broaden our understanding and stretch our imagination about what privacy might entail, and encourage forward-looking, sociotechnical, and reflexive thinking about privacy" (Wong & Mulligan, 2019, pg 10). From a review of the HCI literature, the authors identified various dimensions of the intersection between privacy and design. Researchers have used design to address privacy for four main purposes: 1) to solve a privacy problem; 2) to inform or support privacy; 3) to explore people and situations; and 4) to critique, speculate, or present critical alternatives (Wong & Mulligan, 2019). The authors also outline who is doing the design work and who benefits as a result: 1) by design authorities, for stakeholders; 2) by stakeholders, for stakeholders; 3) by design authorities, for design authorities; and 4) by stakeholders, for design authorities. This work has been influential on this study in pursuing the co-development of privacy needs with trans and queer youth.

Participatory threat modeling is one example of integrating participatory HCI methods with privacy and security research. Threat modeling is a common first stage in cybersecurity research that works to predict potential threats to a computing system (Shostack, 2014). Veseli et al. have also applied the privacy-by-design framework to threat modeling and highlighted the iterative nature of this process. In the design of an identity wallet platform, they identified threats, mitigation strategies, barriers, and adjusted mitigation for each possible feature (Veseli et al., 2019).

In line with previous critiques that privacy and security research practices ignore the role that bias plays, scholarship has initiated conversations about how the positionality of those performing threat modeling informs the kinds of conclusions that are made (Benenson et al., 2015; Slupska et al., 2021). To this end, Pierce et al. have outlined the concept of differential vulnerabilities in cybersecurity as “an understanding of security that recognizes safety as socially contingent, adversaries as unstable figures, and risk as differentially applied based on markers of relational position (e.g. class, race, religion, gender, geography, experience)” (Pierce et al., 2018). Taking into account who determines what counts as a threat, Slupska and colleagues have led participatory threat modeling sessions in which end-users outline their own cybersecurity threats (Slupska et al., 2021; Slupska et al., 2022). By centering those who are directly affected by cybersecurity breaches in the threat modeling process, researchers and designers can provide more realistic measures and protections. This participatory approach is reminiscent of the concept of “personalization from below” in the context of digital data and health services (Suman et al., 2023). Shifting power towards people affected by health services has several benefits: it leads to more practical knowledge about health issues, holds politically significant weight, and “can help making visible the issues, concerns, needs and health priorities of neglected groups” (Suman et al., 2023, pg 4).

Furthermore, prefigurative design provides a conceptual bridge between privacy-by-design and design justice research. Critical sociotechnical scholar Mariam Asad outlines prefigurative design as “*a tool to articulate a vision with community partners to better identify opportunities to leverage existing justice work through research intervention*” (Asad, 2019, pg 10). In this framework, Asad poses five questions around potential harms, who or what is doing harm, and mechanisms for healing in the face of such harms (Asad, 2019). By remaining accountable to possible harms of flimsy privacy and security measures, this study pursues healing and research justice through design.

5.2.2 Privacy and Security in HCI

HCI researchers have incorporated these sociotechnical values to pursue a more practical, effective understanding of privacy and security needs. Previous privacy and security scholars in HCI have advocated for moving away from a one-size-fits-all model of designing for safety (e.g., Tseng et al., 2021; Geeng et al., 2022). Chris Geeng has written about the privacy nuances required to account for queer experiences (Geeng, 2022). They identify in their work that a standard set of safety practices may not be pertinent, realistic, or even desirable for everyone; therefore, approaches to privacy, security, and safety must too be malleable and able to adapt to different users’ ever-changing needs. As an example, queer intimate platform users reject security and privacy-related advice because this guidance commonly conflicts with their joy and potential for creating relationships (Geeng et al., 2022). Through an investigation into sexting, Geeng and their colleagues demonstrate how people who sext use both technical and social strategies to preserve their privacy and security (Geeng et al., 2020). Through this work, Geeng identifies the divide between ideal, standard privacy and security practices and real human behavior. By attending to this gap, researchers have called for providing security advice that is specific, rather than consistent and more contextually situated (Geeng et al., 2022; Redmiles et al., 2020).

Additional HCI work in privacy and security has gone beyond individual responsibilities towards community and systemic levels of protections. For instance, Liang et al. have outlined how state surveillance efforts are reinforced in intimate platform design of sensitive data disclosures like HIV status (Liang et al., 2020). Tseng et al. take on an infrastructural approach to privacy and security measures by reframing orientations around the idea of care work (Tseng et al., 2022). In this shift, privacy and security are concepts that fall under a wider sociotechnical understanding of safety, embracing a holistic approach to technology design that takes complex, social factors into consideration. Additionally, Pyrrho et al. have written about how individuals can challenge larger entities in regards to their privacy: "*the asymmetry of power derives from a contrast between the total transparency of users and the almost complete opacity with which large corporations are protected. In order for them to be held responsible for unfair and discriminatory applications of data (the objective of regulation), it is necessary that citizens can demand information and data from those who use it, and that the origin and flow of that data be made known. The citizens' right to information regarding their data must oblige every entity, public or private, which has used them*" (Pyrrho et al., 2022, pg 8). There are evergrowing ways that corporations perpetuate surveillance of marginalized people through data, calling forth the importance of resistance from multiple levels (Zuboff, 2019).

5.3 Methods

This study occurred in two stages. I first led a series of focus groups and follow-up interviews with people who provide support services for trans and queer youth. Afterwards, I held co-design sessions with members of a previously formed community advisory board, known as the Queer Trans Advisory Board (QTAB). In both stages, I presented and validated previous findings so that each group could provide feedback based on their expertise and knowledge of the experiences of trans and queer youth today. We also contextualized privacy and security in the greater project to design online interactive sex education tools.

Focus Groups and Semi-Structured Interviews with Support Network Members

We conducted three focus groups with 16 participants and seven individual follow-up interviews with people that work or volunteer at organizations that provide social support, legal services, and health-related services to transgender and queer youth. We used snowball sampling for recruitment by inviting national non-profits and those in our personal networks via email. Focus group discussions were broadly centered around validating findings from previous studies. The research team presented previous findings around content, design needs, and strategies for future recruitment. Follow-up interviews focused on how to handle trans and queer youth's privacy and security in an online sex education tool's design. We discussed what privacy and security concerns participants hear about or encounter for trans and queer youth, how they have navigated institutional policies (e.g., COPPA, HIPAA, school-level policies, organizational policies, cultural norms within organizations), among other topics.

Participants consisted of public health policy makers, service providers for trans youth, school-based care workers, privacy and security legal experts, and sexual health platform designers who have experience with a range of direct interactions with trans youth, their peers, parents, educators, and healthcare providers. Approaching our recruitment in this broad sense allowed us to understand privacy and security concerns at a more comprehensive level with multiple perspectives in a trans young person's support network. This decision was intentionally meant to steer solutions away from individual responsibility to manage one's privacy and security and towards an infrastructure of care (Tseng et al., 2022).

Co-Design with Community Advisory Board

Alongside this work, I have cultivated relationships with national partners from LGBTQ+ community-based organizations to elicit feedback on our approach. These relationships have also provided the opportunity to connect with an extensive network of trans young people across the United States and elicit feedback on our recruitment techniques, previously generated insights, and plans for future engagements with youth.

Due in large part to our established connections, we have assembled 20 trans young people ages 16-25 to form a community advisory board (CAB) for upcoming co-design sessions. This CAB was intentionally designed to center the perspectives of Black, Latine, and Asian-American youth; transfeminine and non-binary people; young people living in rural areas and/or localities where legislation is actively attempting to remove their healthcare access; and people who are new to experiences with research. There are increasingly more social support groups for trans young people today, but this group is unique by positioning CAB members as experts of their own lives and drivers of research that affects their own health related issues.

In addition to the aforementioned focus groups and interviews with people within trans and queer youths' support network, I validated previously generated findings with members of the community advisory board. Through an online co-design session, we discussed their own conceptions of privacy and security, their perceived current threats to trans youths' privacy and security, and their ideal way of handling privacy and security in the tool that we are co-developing. Through co-design, CAB members were able to make direct design adjustments to wireframes. A team of student-designers experienced in user experience design and online prototyping provided support to translate CAB members' design ideas into modifications to the wireframes.

Data Analysis

I analyzed this data through reflexive thematic analysis (Braun and Clarke, 2019), guided by several values that I shared with participants in each session. First, trans and queer youth deserve access to tools that can help them learn how to have healthy sexual and romantic relationships, which entails thinking about care work through developing awareness and emphasizing bodily autonomy, among many other important aspects. Next, our methods involve partnerships with trans and queer youth in the development process of the tool, and we are working towards this by involving youth on various levels: as design partners, as community advisory board members, and as research team members. Last, it is difficult and unrealistic to cleanly separate online and offline experiences. Online activity can have implications for offline experiences, and so we hope to understand the holistic lived experiences of trans and queer youth as they relate to privacy and security. Acting as a form of member-checking, the validation of previous findings was an additional analytical method in this study as we fielded responses with both groups of support network members and community advisory board members.

The four tensions—exploitation, membership, disclosure, and allyship—continued to play a role in the methodological decisions I made throughout this study. Considerations for mitigating exploitation was a large motivating factor for forming and involving the community advisory board, as I saw this as an effort to create more participatory involvement. We attempted to distribute power among the research team and community advisory board members and embed multiple ways to shape the direction of the project goals and design specifications. Thinking about exploitation and allyship also pushed us to create additional benefits to participants beyond just monetary compensation. In our interviews to form the community advisory board with trans and queer individuals, we inquired about what they wanted to get out of this experience. There were a variety of interests including pursuing higher education which led us to invite community advisory board members to get involved in further research opportunities. However, one of the biggest goals for those we spoke to was to find comfort in community. Many community advisory board members are isolated as one of the few queer and/or trans people at their schools, for instance, and were most excited to spend time in a space full of young people like them. Thus, it has been vital to help members establish bonds with each other in co-design sessions.

5.4 Findings

We constructed themes from our data around three high-level categories. First, what threats currently exist and from whom? Second, what constraints exist that limit our abilities to intervene? And then third, what are current mitigation strategies that people use to address these threats and constraints? A summary of these findings are presented in Table 8 and Table 9. I refer to findings from the first series of focus groups with support network members as FG1 and findings from engagements with the community advisory board as CAB.

Threats
Parents, guardians, and family members
Peers and classmates
Data brokers
The State
Trans youth themselves

Table 8. Current threats to trans youth privacy and security

5.4.1 Contextualizing Privacy and Security

I initially sought to understand the importance of centering privacy and security when working with trans and queer youth. A CAB member discussed why doing so was valuable: “privacy means the ability to share information that we feel safe and comfortable with sharing, without a pressure to give out more. It means there is a protected space where we can share our stories with confidence they will not be shared widely or we will be subject to hate.” FG1 participants spoke about privacy and security in the context of working with trans and queer youth. Participants from FG1 identified three values and practices that are key to this work—disclosure, agency, and safety.

First, privacy and security are intertwined with disclosure practices. One FG1 participant indicated that “*being secure, feeling secure, often depends on people knowing or not knowing, and what that means*”. They also pointed out that what makes disclosure tricky to deal with is the fact that once that information is out there, you very often cannot take it back. As this participant said, “*you can’t unring a bell*”.

Second, there is a strong emphasis placed on user agency, referring to having control over who knows what information. One CAB member wrote that privacy and security meant “*Knowing* *where my data is going/how it is being used and why!*". Especially when considering the threats that are discussed in the next section, participants identified the importance of having control over one's information.

Third, safety is an outcome of privacy and security from both a physical and emotional standpoint. One CAB member said that "*more than anything I just want assurance that a transphobe isn't going to dox me and then mail me a pipe bomb*" which was received with solemn agreement. Another CAB member called out the feeling of betrayal when privacy and security are compromised specifically when dealing with a sensitive topic like sexual health: "*Privacy and security is safety. There is a lot of shame that can come with sex-ed topics, that some would like to keep private. Minimize the feeling of betrayal.*"

One member from FG1, a privacy and security legal expert, outlined the interconnectedness and importance of privacy and security in a trans young person's development:

> "I think privacy is instrumental to safety. If you don't have privacy and you're a queer youth or trans youth who's already at so much risk of violence, being ignored by a medical system, being neglected by your own family and loved ones, your privacy is kind of the lynchpin holding all of that together. If it collapses, then you're at so much risk, and so it's critical.
>
> It's foundational to expression as well. So not just your ability to keep safe physically in your relationships, but also your ability to have freedom in terms of what you're looking for, what you're interested in, growing when you're a young person, being able to access

> information without feeling chilled is critical to your own growth and who you are and who you want to be.
>
> And I think for trans youth, that's so important because you are in a system where you're going to school and you're maybe subject to school surveillance, you're on a computer that is surveilled by your teachers, your librarians, or administrators. You go home maybe to an unsupportive household, and maybe you're using internet services, maybe you're just reading a book, right? We know that books that have been historically banned in prisons and schools, they're often banned because they're about LGBTQ materials. So it's not just about being online. It's about accessing any information overall. It's about your safety, your physical safety, your relationships, your ability to express yourself, and your ability to learn and grow, which is, to me, everything that kids are doing every single day." FG1, P6

Participants identified two main forms of privacy and security violations: data breaches and unwanted disclosures. With the design of the OISET in mind, one CAB member wrote that "*privacy and security is important for this tool as to not out those who use this resource and may not ready to be out yet*". Many CAB members cited being doxxed as a fear and direct consequence of these privacy and security violations. One CAB member summarized the concern well: "specifically outing their [a trans youth's] identity on the platform and leading to bullying at school, being outed to their parents, and potentially getting into legal trouble depending on the state they reside in."

5.4.2 Current Threats

From there, participants identified five main groups of people that are potential threats to trans young people's privacy and security. First, parents, guardians, and family members. In school settings, FG1 participants who worked in schools discussed how some students used different names and/or pronouns at school than they did at home. They had to keep track of what information parents or guardians were aware of so that they did not accidentally out someone. One public health policy maker described that "*sometimes they're [the students] just very clear, up-front like, 'This is my identity at school, but I have a different identity at home.'*" One CAB member added that privacy and security for the OISET came down to "*safety in situations where a person would be in danger if their family discovered their identity or orientation*".

FG1 members who worked in school settings had to also manage classmates and peers so that they also would not out anyone. One school-based public health policy maker described their experience of preventing classmates from outing each other:

> "A fourth grader wanted to come out as trans in their class or identify as trans in their class. So they were doing this activity in the beginning of the year, and another classmate was introducing them. And the first thing I said was, 'What does the other classmate think of this?' And she was like, 'I hadn't even thought about that.'"

A third group that people talked about were data brokers, or third party groups that threatened reputational harm to trans young people if they were to ever bypass security systems of personal information. One legal expert from FG1 pointed out the "*reputational harms for a child who's been outed*" by expressing that "*if a data broker wanted to leak this or a hyper conservative news outlet who goes where, that sort of thing can actually cause a huge amount of problems*." Furthermore, a CAB member elaborated on their concern around what outside entities might do with their data: "it is dangerous for strangers, corporations, or governments to have access to trans youth's information, where they could use the data to single people out, or twist words/the truth to suit their own needs." CAB members were additionally conscious of how platforms, particularly Meta and Instagram, facilitate unsafe online experiences. They speculated around what these platforms could do with their power. One CAB member worried about targeted, harmful ads: “*Meta has before allowed ads to target very specific demographics, and it would be possible to, for example, make an ad that was targeted only to trans youth and would direct them to something nefarious.*” Another CAB member raised flags regarding tracked data: “*similar to how states are using instagram messages as evidence for someone planning an abortion, wouldn’t doubt they want to use them as evidence of trans youth planning healthcare etc. where it’s now illegal. Meta has no ethical/moral issue with sharing the data with law enforcement.*”

There were also concerns of governmental intervention especially in states that are introducing legislation to ban or limit access to gender-affirming care. One FG1 participant spoke about their experience after a government official in their state commented that any kind of affirmative healthcare or mental healthcare for trans youth was amount to child abuse. In the aftermath, this participant said their organization “*had families from all over the state reaching out to us asking, "What do we do? My kid tells me that he's my son, and [...] I'm not going to force him to keep his hair long. Am I going to be in trouble with the state?*" With the ever-growing number of bills being introduced and passed in numerous states in the US, these concerns are becoming more common.

Members of the CAB identified an additional threat to trans and queer youths’ privacy and security: themselves. They warned against trans and queer youth providing information about themselves that others might use maliciously. They discussed an example of a trans young person posting to social media that reveals where they go to school, which evil actors could then use to dox and harass them. Here, CAB members emphasized the importance of educating trans and queer youth to be conscious of what information they are making public. Through the addition of this category, it is important to point out that each poses different levels of threats. These threats map onto individual, communal, and structural levels that call for different kinds of interventions. Trans youth involuntarily revealing their personal information points to a need to educate online users and platform-mediated prevention of such disclosures. Threats from family members, peers, educators, and other people in trans and queer youths' networks call for trauma-informed protocols that care for trans and queer youths' wellbeing. State surveillance and punishment motivates organizational policies and laws that, for instance, prevent the collection and merchandising of personally identifiable information for marginalized people. Across these five pieces, however, there are underlying power relations between and among each threat that requires further interrogation. Threat modeling, then, requires a deeper questioning of the outcomes of this process towards thinking about how different levels of threats call for distinct constraints and approaches for mitigation.

5.4.3 Social and Technical Constraints

I outlined a number of constraints that inhibit designers' ability to fully cover privacy and security threats, categorized into social constraints and technical constraints.

Social constraints for FG1 members revolved around protecting privacy and security while also navigating through different contexts. School-based care workers discussed using consistent pronouns and names under different contexts. One FG1 participant shared that it felt like they were often "*walking this tight rope of which pronouns they use at school, which pronouns they use at home, which names so kind of juggling a lot of different spheres and trying to maintain confidentiality while I'm doing that.*" In addition to this, another FG1 participant pointed out that language evolves and thus, their ability to maintain confidentiality shifts as well. They pointed out that "*when a trans young person is talking about their identity and talking about being out or not, it's not always clear that those words are being used the same way by any two trans kids, let* *alone by the adults in their life."* Additional social constraints revolved around parental or guardian involvement. A participant from FG1 indicated that providing services for trans and queer youth is difficult when they live in a home where their identity is a secret, which is more common for youth under 18. School-based members of FG1 also experienced trouble when they had to keep information from parents at the request of the students. Guardians, parents, and other adults can also impose their own beliefs about privacy and security onto youth. One FG1 participant expressed that "*there are trans kids who might be fully comfortable with being out and open about being trans. And it's the adults in their life who are more concerned about privacy or security*."

An additional social constraint is that there are legal and organizational barriers to access that present major challenges to protecting people's privacy and security. A FG1 participant laid out a possible scenario given the political climate in some states:

> *"So if you're in an unsympathetic environment, in a state that has passed laws that are penalizing trans youth, and you are seen as violating the law because you're facilitating their access to necessary healthcare services and the law enforcement comes to you with a warrant and they say, 'We see this child here is getting those services. We know they visit your clinic. We're going to give you a warrant just for their data.'"*

A legal expert in FG1 also called out the individual responsibility of maintaining and protecting one's own data. As they discuss, "*the more we talk about, 'You need to do all these things to keep yourself safe,' the more we put the onus on the individual to protect themselves when really, that's not what's happening here. Every time I go somewhere, I'm not going to turn off my phone. Every time I need to figure out directions on how to get there, I'm not going to use a specific browser, right? It's not possible to expect people to hold this heavy of a burden. And so what I would say* *instead is we need to be able to put the onus on the entity that could do the most harm and that's organizations, it's law enforcement, it's legislators, right? And so burden shifting, I think, in that way is really important.*"

Participants also identified eight reasons that make privacy and security protections difficult from a technical standpoint. First, a participant who is sexual health platform designer talked about the time and effort it takes to oversee content moderation. This is especially important to keep in mind when platforms are introducing interactive elements where people are coming into contact with other people. Another FG1 member raised concerns around consent fatigue, questioning: "*How do we make it so that we're not feeding into consent fatigue? So if you're a user going through-- you're not reading privacy policy. You're just clicking through, right? How do we make sure that [we get consent] when we actually need your consent*". In addition, an FG1 participant discussed how people have different thresholds and preferences for their privacy. Where there are people who are not concerned about their privacy, there are other people who might not be out and thus the importance of maintaining that control over their information is heightened. Furthermore, traceable data can be useful to online experiences in some instances, with one participant using email and password resets as an example. Another FG1 participant connected technical protections with potential shame as they described a potential solution like an exit button might "*automatically bring some type of taboo to the site*". Next, participants pointed out that platform policies that are meant to maintain privacy and user data can only go so far in their protections. Finally, one participant discussed even the best privacy and security measures in place cannot ever fully protect trans and queer youth. As they described: "*in a world where these laws are being passed and in a world where there are parents who are trying to make their kids not trans, there isn't one good option*".

5.4.4 Social and Technical Mitigation Strategies

Next, I outline a number of mitigation strategies to account for threats to privacy and security but also must contend with the previously mentioned constraints. These have also been separated into social and technical categories.

In regards to social strategies, participants from FG1 suggested practicing language to maintain consistency across contexts and when engaging with youth. For those who interact with trans and queer youth and others in their network, this kind of preparation is key to preventing any unwanted disclosures. Participants additionally considered repair work in response to times when harm has occurred by directly addressing harmful behavior. Doing so, as participants pointed out, is important to creating an environment of safety and privacy. FG1 participants also suggested involving youth when making decisions about what information is being kept private. A member of FG1 that designs sexual health platforms also recommended establishing ongoing consent practices. They described their own consent processes for generating content based on interviews with youth on their platform:

> “We take great care to [...] make sure they understand consent, that they are allowed to revoke this interview. They're allowed to stop the interview at any time. We explicitly say how the interview will be featured on the website. They have the permission to remove their name at any time, to remove the interview. And so it was one way for us to create that community and to create those stories, those first-person stories that are so important to our understanding of our health and identity but recognizing that with that comes some risks and that we do everything in our power to share what those risks potentially could be and also allow people to remove, stop, or opt out at any time.”

In this instance, designers value agency, transparency, and consent throughout youth involvement in platform experiences. Perhaps most important to highlight in regards to social mitigation strategies revolves around thinking about who should be held accountable to keep users and their data protected. One FG1 participant made the case for a shift away from the current paradigm that forces individuals to carry the burden of protecting themselves and their data, without any assistance from platforms, organizations, or other entities with power. As they stated:

> “The more we talk about, ‘you need to do all these things to keep yourself safe,’ the more we put the onus on the individual to protect themselves when really, that's not what's happening here. Every time I go somewhere, I'm not going to turn off my phone. Every time I need to figure out directions on how to get there, I'm not going to use a specific browser, right? It's not possible to expect people to hold this heavy of a burden. And so what I would say instead is we need to be able to put the onus on the entity that could do the most harm and that's organizations, it's law enforcement, it's legislators. And so burden shifting in that way is really important.”

With this quote in mind, platform designers should plan privacy and security policies such that users are not alone when managing their own online risks.

Participants also identified six forms of technical mitigation strategies. First, one method for protecting users from harm is to simply not allow spaces where harm can occur to exist in the first place. One sexual health platform designer we spoke with said that their platform does not have a discussion board, even though it is a common feature, for this reason. Participants also suggested combining online and offline support for trans and queer youth as well as educating online users about privacy policies and how to securely manage their personal data. The sexual health platform designer in FG1 also discussed prioritizing user agency over their platform experience. On their platform, users “can come in and take a proactive approach. So if someone wants to search sexuality and pleasure, they can do that without being bombarded with potentially other resources that may be triggering." Data management played a large role in the suggested technical mitigation strategies, leading to being intentional about what data are being tracked and why. The last technical mitigation strategy that participants identified involves moving away from blanket approaches to using and/or prohibiting data usage. One participant from FG1 highlighted that tracked data, especially in aggregate form, can provide utility for community efforts. As they put it:

> *"It's so important to keep a lot of these data because it benefits the community. Not just all those things that we like to do but in the ways that we are harmed uniquely. It's important to keep information about the rate of COVID deaths for LGBTQ people. It's important to keep information about where prep is available in certain communities, who gets it first, and how expensive it is, right? There are certain data sets, especially around research, that I would argue if you just say we just delete them or we imposed data minimization, that would actively harm the community."*

With this quote in mind, blanket protections for user data might not always be the best decision, motivating further inquiry into what data are useful and how. A mitigation strategy to protect users can still involve the collection of data, as long as there are intentional ways we can draw from this data to make informed decisions and interventions.

	Social Factors	*Technical Factors*
Constraints	Difficulty maintaining consistency across multiple situations Language evolves, making it difficult to stay consistent Providing services for people differs for those under and over 18 Balancing adult opinions when providing services to minors	Data that are traceable can also be helpful Content moderation is hard Mitigation strategies can create taboo Consent fatigue Policies are insufficient at providing

	Legal infrastructures that work against privacy Solely focusing on individualized approaches are impractical and unsustainable	protections Navigating different preferences for privacy Lack of consistency across systems There is not perfect solution
Mitigation Strategies	Practicing language prior to engagements with youth Consistent support/language Repair work to respond to when harm has occurred Involving youth input into how to respond Establishing ongoing consent practices Burden shifting away from the individual	Combining offline and online support Not providing spaces where harm can occur User agency over platform experience Being intentional about what data are being tracked Intentional uses of data, away from blanket approaches to using/prohibiting data use Education about privacy policies and managing personal data

Table 9. Summary of social and technical constraints and mitigation strategies for trans youth privacy and security.

5.4.5 Current Design Patterns for Privacy and Security

After identifying these threats, constraints, and mitigation strategies, I also conducted a content analysis (Hsieh and Shannon, 2005) of 13 existing sexual health resources and platforms to understand how current technologies handle privacy and security, shown through Table 10. Through an app walkthrough method (Light et al., 2018), I tracked what features each resource offered and if they had any specific privacy features.

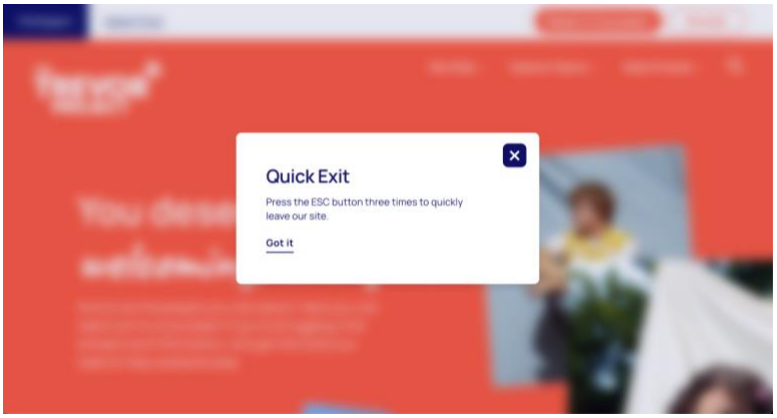
Sexual Health Resource	*Features Offered*	*Privacy Features*
Queering Sexual Health Education	blog posts with resources, self-assessment quizzes, definitions, information,	Quick Hide, data education

	linkage to services in local area, chatbot, text and phone lines	
Asexual Visibility and Education Network	definitions, information, FAQ, forums, videos, links to other asexual communities/pages online, question support via email	n/a
Accord Alliance	FAQ, support groups, models of care for DSD	
Sex, etc.	Chat with Planned Parenthood, blog posts, FAQ, videos, definitions, information, polls, clinic finder	Privacy policy
Scarleteen	message boards, sms service, live chat, definitions, information, personal experiences, tag system	Privacy policy, data education
Advocates for Youth	facts sheets, information, message boards	Privacy policy, data education
UCSF Trans Care	HRT facts sheets, information	n/a
Seattle Children's Gender Clinic	information, facts sheets, videos	Privacy policy, data education
Trans Care BC	information, print resources, contact form, linkage to resources in local area	Privacy policy, data education
WEAVE	live chat, information, email list, facts sheets	Exit site button, privacy policy
LGBTQIA+ Safer Sex Guide	information, links to other articles/resources	Privacy policy, data education
safersex	information, definitions, blog posts	Privacy policy, data education
Trans Tracks	Transition tracking	“deep cover mode”

Table 10. Features and privacy settings for thirteen existing sexual health platforms.

At a high level, there are three current design patterns for protecting privacy and security on trans/queer health resources and platforms. First is through education, primarily through privacy policies. Eight out of thirteen platforms had privacy policies that at minimum laid out how they handled user data. Many of them did mention that they only sold particular sets of user data to third-party analytics services. Of the thirteen, seven platforms listed dedicated sections that explained the implications of providing personal data to the site, emphasizing that no site is ever truly secure. However, the overall approach was to leave it to the individual person to decide how much information to provide and thus how much risk they were willing to tolerate.

Another design pattern was a “quick exit” button found on two websites. Here, users can click a readily available button that will take them off the page and onto somewhere more innocuous. Please see Figure 1 for an example. One participant debated whether this kind of feature instilled a sense of shame or taboo to the user experience of being on that site. Having it so readily available might be a constant reminder that what a user is looking at is something they need to hide. Members of CAB enjoyed quick exit options and suggested that a future online interactive sex education tool for trans and queer youth utilize this feature. They noted, however, that users should be able to control whether the quick exit option appears or not.



Quick Exit

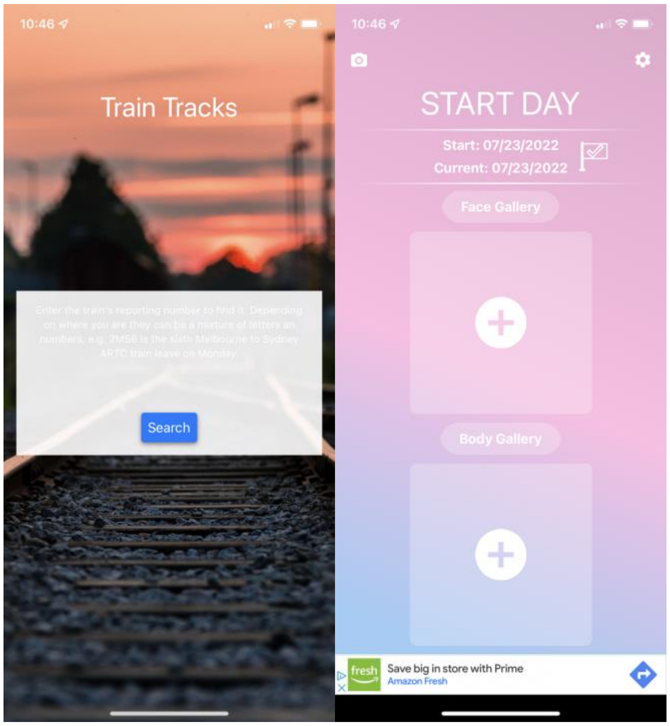
Press the ESC button three times to quickly leave our site.

Figure 1. Quick Exit feature from The Trevor Project[10] website.

The third design pattern is “camouflaging”. A specific mobile app called Trans Tracks, a platform where users can track the progress of their transitions, has two modes. In one mode, called “deep cover mode”, the login page and app icon change from the blue and pink trans colors to a more covert design. Additionally in this mode, the login page becomes what appears to be a place to check train schedules. When the user enters their password, they are then brought to the original transition tracking page. One CAB member had direct experience using Trans Tracks but was unaware of the camouflage feature until discussed in a codesign session. Reflecting on this, they suggested greater visibility towards these features, stating “*i use transtracks! but also i didn't know that feature (camouflage mode) existed so maybe more visibility regarding these features so people know about them. Maybe when you first open the app you get the choice with a message stating (you can change this at any time in settings)*”.

---

[10] https://www.thetrevorproject.org/



Enter the train's reporting number to find it. Depending on where you are they can be a mixture of letters an numbers, e.g. 2MS6 is the sixth Melbourne to Sydney ARTC train leave on Monday.

Start: 07/23/2022
Current: 07/23/2022

Figure 2. Camouflaging on Trans Tracks[11].

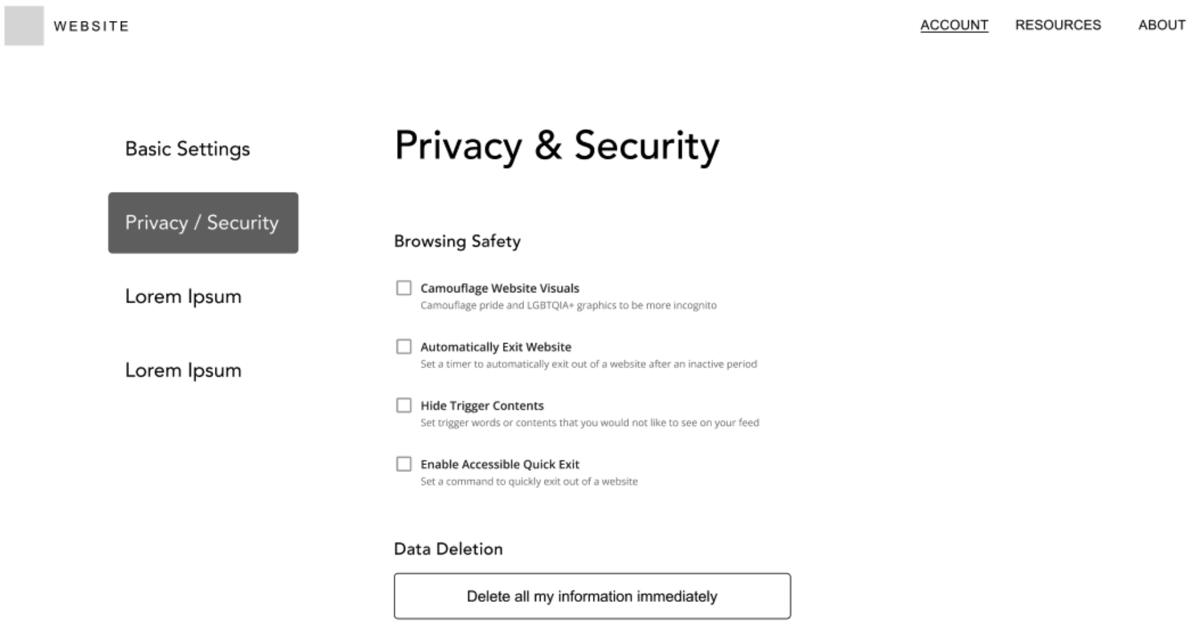
5.4.6 Envisioning Privacy and Security Settings for an OISET

When asked about their ideal ways of handling privacy and security in a future, online, sex education tool for trans and queer youth, members of the CAB named several design values—protection, personalization, and transparency. One CAB member wrote that they wanted to see "*protection of personally identifying information, account data, search history, articles viewed, etc. Should never be shared or accessed outside the tool*". CAB members also wanted control over their settings, with one person wanting to be able to opt in or out of data tracking and another wanting users to be able to change their names easily. Another sought out "*personalized security preferences like ability to have your post/comment history (if we even have those) public or private*." Another CAB member called for an OISET platform to be transparent about its privacy and security settings by providing descriptions and reasoning for various features.

---

[11] https://transtracks.app/

Figure 3 and 4 depict wireframes developed by Andy Moon, a part of the student-designer team. Working off of feedback from CAB members, Andy drafted the following screens to demonstrate how the OISET might handle privacy and security settings. There are several features including options to camouflage website visuals, automatically exit the site after a set time, hide trigger content through a platform-wide tagging system, quick exit options, and the option to delete all stored user data. In co-design sessions, Andy and the student-design team collected feedback from CAB members to validate their interpretations of previous feedback. CAB members were positive about these privacy and security features, though they raised concerns about whether a user must have an account created to access these features. They suggested that privacy and security features should be available to anyone who visits the platform, which led to the development of Figure 5 which prompts users who are new to the site to configure their privacy and security settings. CAB members provided further feedback on how to hide triggering content. While they felt positive about filtering out content that users do not wish to see, they recommended that the platform should be transparent about why it is filtering certain content. Figure 4 illustrates an example of this by conveying to the user that content is being blocked due to the user's specific trigger warning settings.



Privacy & Security

Browsing Safety

☐ **Camouflage Website Visuals**
Camouflage pride and LGBTQIA+ graphics to be more incognito

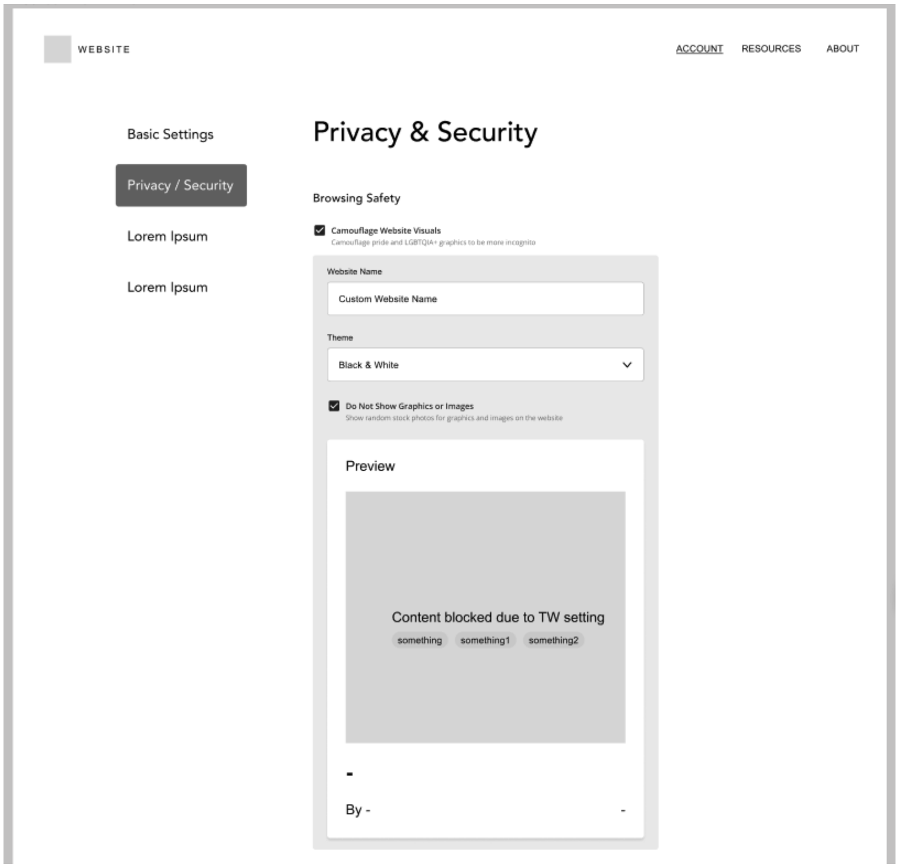
☐ **Automatically Exit Website**
Set a timer to automatically exit out of a website after an inactive period

☐ **Hide Trigger Contents**
Set trigger words or contents that you would not like to see on your feed

☐ **Enable Accessible Quick Exit**
Set a command to quickly exit out of a website

Data Deletion

Figure 3. Envisioned privacy and security settings on an OISET



Privacy & Security

Browsing Safety

☑ **Camouflage Website Visuals**
Camouflage pride and LGBTQIA+ graphics to be more incognito

Website Name: Custom Website Name

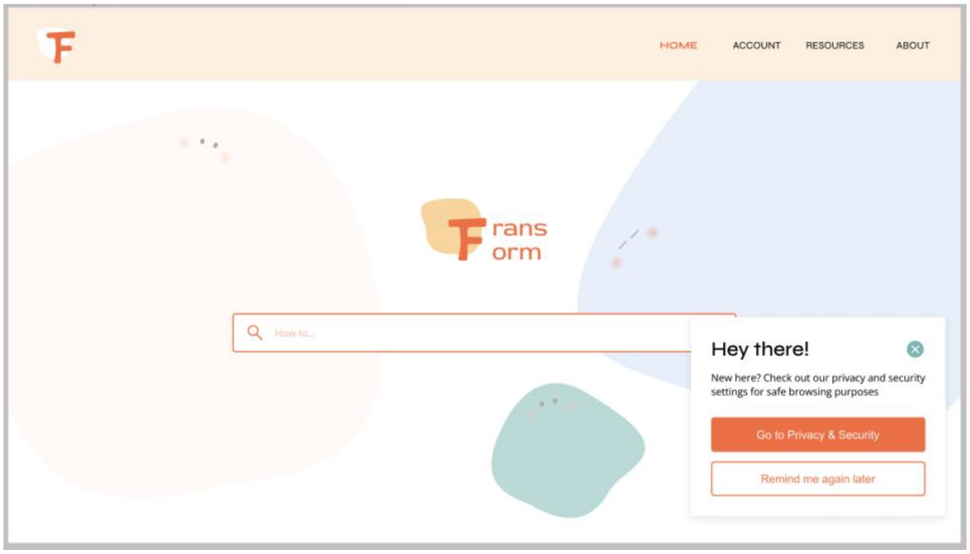
Theme: Black & White

☑ **Do Not Show Graphics or Images**
Show random stock photos for graphics and images on the website

Preview

Content blocked due to TW setting

Figure 4. Envisioned privacy and security settings on an OISET



Hey there!

New here? Check out our privacy and security settings for safe browsing purposes

Figure 5. Envisioned privacy and security onboarding for new OISET users

5.5 Discussion

Through engagements with trans youth and those who support them, I have identified current threats, constraints, and mitigation strategies for privacy and security. As such, this study makes several contributions to privacy and security literature as well as further develops design needs for an online, interactive sex education tool for trans and queer youth.

First, I outline a current threat model for the privacy and security of trans youth. I identify five threats: parents, guardians, and family members; peers and classmates; data brokers; the State; and themselves. We also outline social constraints (e.g., difficulty maintaining consistency across multiple situations, evolving language, balancing adult opinions when providing services to minors, legal infrastructures that work against privacy, and the impracticality of solely focusing on individualized approaches) and technical constraints (e.g., data that are traceable can also be helpful, content moderation is hard, consent fatigue, different preferences for privacy). Third, we identify social mitigation strategies (e.g., providing consistent support/language, involving youth input into how to respond to harm, establishing ongoing consent practices, burden shifting away from the individual) and technical mitigation strategies (e.g., combining offline and online support, not providing spaces where harm can occur, prioritizing user agency over platform experience, educating about privacy policies and managing personal data).

Next, we review design patterns and offer speculative features to address user agency in controlling how their data are managed through an online interactive sex education tool. We distinguish three existing design patterns to maintain privacy and security: education via privacy policies, quick tools for exiting, and camouflaging. Co-design sessions surfaced various features for the OISET: personalizable website visuals, automatic website exit, hiding triggering content, quick exit hotkeys, and overall data deletion.

Third, I make a methodological contribution to participatory threat modeling towards a community approach to privacy and security for trans and queer youth. Through this community orientation, I work towards an infrastructure of care by involving members of a marginalized group's support network in brainstorming privacy and security protections (Tseng et al., 2022). Previous work has shown how participatory engagements with marginalized people can actually reinforce harm by reminding them of the difficulties they face (Harrington et al., 2019), and so a community-collaborative approach to threat modeling may be able to mitigate any undue distress. This study's methodological extension also includes a sociotechnical approach to threat modeling to include social threats, constraints, and mitigation strategies. Here, we call for cybersecurity researchers to account for non-technical dimensions. As we demonstrate, protecting privacy and security is not solely an online experience; care must involve social, community, and structural support as well. Understanding how offline and online experiences are interlinked and influence each other can only come from participation of those who are directly affected.

By providing the sociotechnical landscape of privacy and security concerns for an online interactive sex education tool for trans and queer youth, I draw from these findings to outline elements of a queer privacy-by-design framework in the following section.

5.5.1 Queering Privacy-by-Design

While privacy-by-design acts as an overall protection framework, critics have raised concerns over its generalizability. Previous scholarship has pointed out that privacy-by-design is an idealized approach that is less equipped to identify and navigate situational needs. PbD falls short when it has to consider more complex social factors such as establishing trust in a system required for users to be fully protected and structural barriers like laws and regulations (Alkhatib et al., 2020; Stark et. al., 2016). As such, this study works to incorporate sociotechnical principles into privacy-by-design standards for queer users constructed through the qualitative data from this study and supporting literature.

Principle 1: Weighing the tradeoffs of data storage

Our findings suggest that there are advantages and disadvantages to user-provided data in shaping their platform experience. One feature surfaced through codesign sessions was creating a bank of trigger tags to hide any content that a user does want to see. However, this feature hinges upon the user providing information about themselves and what they find triggering. Future features that community advisory board members have suggested include databases of trans and queer-friendly healthcare providers in a user’s area, but this also relies upon user data that could leave them vulnerable to being doxxed and additional losses of privacy and security. It is possible, however, to collect data, use it to meet user needs, and then delete them without storage. Therefore, this principle elicits designers to reflect upon the tradeoff between personalization and privacy and security. There will certainly be features that can optimize the user experience, but designers must weigh potential benefits with possible risks.

Calling back to a technical constraint described in Section 4.4.3, data that are traceable can also be useful. Participants raised the value of collective, anonymized data for similar reasons for contact-tracing for COVID-19. Kevin Guyan discusses this tradeoff of data collection in his book *Queer Data: Using Gender, Sex and Sexuality Data for Action* by describing the representational value of considering who counts (Guyan, 2022). Data is entrenched in critiques around who gets to decide who or what counts but, importantly, can lend legitimacy to social movements and LGBTQ people. Data can be structurally prescriptive; as Guyan characterizes it, "*data enables us to know how many people identify with a particular identity group, this group's experience of services such as healthcare and education, and relative levels of advantage and disadvantage (which involves comparing data for one group against another group or a defined benchmark). Data can expose the effects of patriarchy, misogyny, homophobia, biphobia and transphobia on the systems and structures we rely upon to navigate our everyday lives. Whether it's differences in the use of transport networks, perceptions of crime or success in education, data is central to the diagnosis of a problem and decisions made about how to respond*" (Guyan, 2022, pg 16). In contrast, Foucault warns against the trap of visibility, making connections to surveillance and subjugation. Drawing from a present example, researchers have come under fire for amassing a dataset of 1 million images of trans people through various stages of transitioning, extracted involuntarily from Youtube for training a facial recognition algorithm (Gault, 2022). Even more damning, the dataset was left unprotected and publicly accessible through an algorithmic audit (Keyes & Austin, 2022).

As such, privacy and security researchers and practitioners might consider the following questions when designing online tools for trans and queer users: What is the minimum amount of data or information necessary to access different features? Are there ways to provide different experiences for features based on how willing a user is to share their data? To what extent can designers provide a useful experience by collecting but not storing user data?

Principle 2: Remaining attentive to state surveillance

One looming threat to security and privacy is state surveillance, which participants in this study notably named as one of five current threats to trans and queer youths' privacy and security. This form of surveillance is a significant tradeoff for platform-mediated data storage, and the history of platforms selling sensitive information makes these fears certainly feel extant (e.g., Grindr selling HIV status data to third-party entities) (Singer, 2018). Along with Jevan Hutson and Os Keyes, I previously identified the role that design can play in assisting and/or circumventing state surveillance, particularly of HIV data on intimate platforms like Grindr (Liang et al., 2020). This particular structural orientation is especially necessary for cybersecurity researchers because of the growing power that local and state governments are amassing to surveil and punish trans and queer people in the United States. Platform designers, then, should consider what protections can be set in place, either design-based or policy-based, that prevent the exploitation of sensitive user data?

Principle 3: Designing to obscure data

Evidenced through current design trends to camouflage or enable options for quick exits, one principle for a queer PbD framework involves designing to obscure data. This principle works alongside two design needs identified in Chapter 4, designing for safety and designing for inclusion. As our findings suggest, there are an array of privacy and security threats that trans and queer youth face today. These online threats extend into everyday life; for instance, a trans young person who has been unwillingly outed to their families may get forced out of their homes and into a period of houselessness. The consequences of privacy and security breaches can range from mild to severe and, as such, platform designers should consider scenarios that pose the greatest harm.

In some cases, this may mean working around what is legal or permissible, especially in the current political climate where a growing number of state governing bodies are attempting to pass legislation that would prohibit access to gender-affirming care and more. As of March 2022, the Idaho house of representatives has passed a bill that would “criminalize gender-affirming medical procedures for transgender youth and make it a felony punishable by life imprisonment for anyone who helps a child travel across state lines to gender-affirming healthcare” (Yang, 2022). Idaho’s house of representatives are not alone in these efforts either. 22 states have introduced bills to “ban best practice medical care for transgender young people ” in 2021 alone (Movement Advancement Project, 2021). In the face of such legislation, I question what role design can play in countering these oppressive limitations, either through data obfuscation or by other means. Through an integration of Asad’s notion of prefigurative design, a queer PbD approach can provide paths to political resistance and trans and queer justice. Designers may consider the question of “How can PbD principle embedded into a system’s design help users circumvent policies?”

How to do this exactly is still an open question, but drawing from how people in this study characterized privacy and security in the context of working with trans and queer youth, designing to obscure data should involve disclosure, agency, and safety. Considering agency, in particular, points to giving users control over what data is public, to what extent, and to whom.

Findings in Section 4.4.6 support this principle as well, where CAB members suggest abilities to opt in and out and transparency around what data are tracked and why.

This principle of designing to obscure, however, is not a blanket approach; it also entails careful consideration of what not to hide and instead make transparent. As I have learned from participants in this study, transparency and explaining to users why certain features appear the way they do establishes trust in a platform. For example, CAB members discussed a feature where users can filter out content on the platform that they might find triggering or they just do not wish to see. While the design team interpreted this feedback and created a blur effect on anything the user wanted to exclude, CAB members suggested that users should be able to know why the platform was obscuring specific content. As a result, the design team added text to communicate to the user reasons for this decision, emphasizing user agency based on their preselected filters.

This design principle is not contained to just considering how we build technologies for trans and queer youth either. Given recent calls to stop using menstrual tracking apps, for example, the need to account for multiple levels of covertness is one that the design community needs to be prepared for. Because the stakes are high *now*, not just for people who are trans or for people who menstruate, and how we go about navigating this question is a matter of survival for many.

5.6 Relation to Dissertation

In this chapter, I demonstrate that while a traditional privacy-by-design framework is beneficial for being proactive about privacy and security in technology design, there are gaps in such an approach when it comes to designing an online interactive sex education tool for trans and queer youth. To address the space left behind, I make a methodological contribution to cybersecurity threat modeling by first, integrating participatory methods involving those who are directly affected (i.e., trans and queer youth) and second, extending threat modeling to consider sociotechnical dimensions. This chapter continues to support this dissertation's thesis statement of: designing health technology interventions that shape the life experiences of queer people requires an understanding of how their holistic needs converge and diverge from other groups. Existing design paradigms fall short when designing with/for queer people, which necessitates alternative techniques for designing for health equity. By bridging the sociotechnical divide in privacy and security research through participatory methods, this study's contributions work towards a broader infrastructure of care for trans and queer youth. When considering how to design technologies for social movements, Ghoshal and Bruckman have similarly highlighted how privacy and security are key components in establishing trust in computing systems (Ghoshal & Bruckman, 2019).

To underscore the importance of privacy in sex education, privacy scholars Charles Fried and Danielle Citron link privacy and security to our capacity for love and meaningful relationships. Fried writes that "to make clear the necessity of privacy as a context for respect, love, friendship and trust is to bring out also why a threat to privacy seems to threaten our very integrity as persons. To respect, love, trust, feel affection for others and to regard ourselves as objects of love, trust and affection is at the heart of our notion of ourselves as persons among persons, and *privacy is the necessary atmosphere for these attitudes and actions, as oxygen is for combustion*" (Fried, 1968, pg 475, emphasis added; Fried, 2013; Citron, 2022).

Chapter 6. Discussion

This chapter consists of two parts. In the first—*Connections*—I link the four tensions outlined in Chapter 3 to the studies depicted in Chapters 4 and 5. Here, I demonstrate how I have situated exploitation, membership, disclosure, and allyship into the broader context of Project OISET. By doing so, I provide an example of how to translate these values and questions into practice for future HCI researchers who are invested in engaging marginalized people in their research. The second part of this chapter—*Reflections*—looks across themes from Chapters 3, 4, and 5 to develop commitments for those invested in designing health technologies with marginalized people.

6.1 Four Tensions in Project OISET

Given its prevalence throughout my doctoral research, the lessons from the study depicted in Chapter 3 have and continue to influence my position and methods in Project OISET. In the spirit of reflexivity, I discuss below how each tension manifests in this dissertation and how I look to address a range of ethical concerns. By outlining my own reflections, I exhibit for other researchers looking to navigate these tensions in their own work how to think through each without the expectation of a clean resolution.

Exploitation: This tension pertains to two kinds of exploitation, an unequal give and take that sees researchers benefitting while participants get little in return and tokenization of research team members. Regarding the former, I take up strategies that HCI researchers I interviewed identified, including expanding our definitions of compensation; maintaining relationships with participants after a study; setting expectations for relationships before, during, and after the study; teaming up with community partners; member-checking data; and making participants feel comfortable in studies. In terms of the latter, I am cognizant of how others might tokenize me and how I might tokenize collaborators. I have been particularly aware of this as I reflect on how our team would benefit from additional perspectives from people of color.

I have focused on my own role in a pursuit to mitigate the harms enacted through exploitative research practices, but there are limitations to this perspective. First, one person alone cannot completely take on the full effort required to shift burdens away from marginalized people in research. Collective action from a research team, towards a culture of care, is better suited to making a meaningful impact. Reflecting upon power dynamics even within the research teams I have partnered with, efforts from junior scholars with less power can only go so far. Structural barriers (e.g., Institutional Review Boards, publishing norms of a field) are more easily navigable when researchers with more power step in. An additional limitation to addressing exploitative norms in research is time and resource constraints. In my engagements with trans and queer youth, I am conscious of their busy schedules and lives and thus have had to adjust programming accordingly, at times running out of time to lead a discussion on the community advisory board’s leadership structure, for instance. Members of the CAB have joined meetings during their school’s lunch hour, on the weekends, and in between their work schedules, and so I have had to make concessions in running co-design sessions. For instance, our initial meetings lasted for two hours that occurred once a month, and I have since adapted to offer one-hour sessions twice a month to accommodate QTAB members’ school and work schedules. This decision to shorten our meeting times comes with significant trade-offs such as being unable to dive deeply into topics and having limited time to maintain rapport with each other. I have also made all research materials available after meetings so that anyone who was unable to attend could add their perspectives asynchronously. Over the holidays, I did not schedule a synchronous meeting time and there was little engagement with asynchronous activities during this time, which helped me learn to not fully rely on a fully remote approach.

I additionally examine questions from Decolonial Studies scholar Linda Tuhiwai Smith to think critically about partnerships, costs, and benefits: “Whose research is it? Who owns it? Whose interests does it serve? Who will benefit from it? Who has designed its questions and framed its scope? Who will carry it out? Who will write it up? How will its results be disseminated?” (Smith, 1999). In a similar vein, Minkler provides a set of ethical challenges in CBPR: “Did the impetus for the research come from the community? Is attention given to barriers to participation, with consideration of those who have been underrepresented in the past? Can the research facilitate collaboration between community participants and resources external to the community? Do community participants benefit from the research outcomes? Is there attention to, or an explicit agreement between, researchers and community participants with respect to ownership and dissemination of the research findings?” (Minkler, 2004). Thinking across both sets of questions, I have sought out design partnerships with trans and queer youth in Project OISET that bring together expertise of the research team with the knowledge of trans and queer youth partners. Combining my own training in methods with students’ user experience design and research skills and trans and queer youths’ lived experiences has been a careful, intentional effort to distribute responsibility and influence over the project’s direction. In pursuit of inclusive and equitable participation in co-design, I have been intentional about how members of the community advisory board benefit from being a part of this study. In addition to being paid for each meeting, we have responded to CAB members’ interest in further research opportunities. Currently, 3 CAB members are involved in a systematic review study looking at the diversity of representation in studies of trans youth, led by one of our colleagues. We have further plans for a series of career panels, networking with trans and queer people, and attending a conference together. Additional benefits to engaging with the QTAB include a heightened attention to power differentials in the research process and support for our future recruitment efforts. Additionally, we connect youth with other trans and queer youth across the US which can be especially important for those who are isolated or lack a sense of belonging or community.

In theory, I learned how entanglements with exploitation are never fully resolved, and in practice, I have felt both the inherent need to work out every ethical problem and the acceptance that this is a never-ending pursuit. As part of this messy embrace, I have had to divest from and interrogate my own pride and idealized dreams for the impact of my research to understand that the contributions of this dissertation alone will not eradicate the pain and harm that stems from transphobia, homophobia, racism, capitalism, and more. As I can attest, working through this particular tension of exploitation is uncomfortable and humbling, yet I argue that this exact quality is what makes such a pursuit ultimately worth the trouble.

Membership: In this tension, we lay out how having shared experiences and/or identities with participants can enrich the research process through stronger rapport, participants not having to explain everything, and more. We also discuss how membership has its limitations, given intersectionality and the multiple axes of oppression. This tension of membership is particularly pertinent for me to consider as I have shared membership with the trans and queer youth. This grants me some insight into the lives of trans and queer young people in that I can understand what it feels to be different from the norm. Simultaneously, there are many ways that my life experience diverges from those I work with, and so I cannot ever fully know what it is like to be them. In this regard, I have struggled over the course of this project with my place in this research project, waging a longstanding internal debate of whether or not I was the best person to do this work. And yet, despite feeling unsettled with my own limitations, I have chosen to move through research activities while consistently reflecting upon this conflict. To hold myself accountable, I have also committed to documenting the ethical considerations made in my work to strengthen my contributions.

In addition, Rosenberg & Tilley identify a staircase of insider/outsider research involving trans people that consists of four levels: a ground level with no inclusion of trans experiences, a consultancy step where trans people supply their experiences with researchers who are outsiders, an employment step where outsider researchers compensate trans people for their labor in research, and finally a leadership step where trans people trans people are in charge of a research study (Rosenberg & Tilley, 2021). I have strived towards the upper levels of this model where trans and queer youth are both drivers of the research and compensated for their labor, shown through the considerations outlined in the discussion of exploitation above. However, the trans and queer youth we partner with have their own lives and priorities outside of the study parameters, and thus I must respect their boundaries as I work towards higher levels of involvement. A final parameter to consider is the bounds of the grant that supports my design partnerships with trans and queer participants. While I work to establish roles for trans and queer youth to drive the research, we must still adhere to our grant's aims. Thus, there are ways for trans and queer youth to steer the research's direciton with limitations, demonstrating that true design partnerships are difficult to uphold within existing research funding structures.

Disclosure: The tension of disclosure primarily manifests through requests for positionality statements that are just thinly veiled demands for identity-based disclosures. In understanding that disclosure of my identities can be both advantageous and detrimental, I often choose to not disclose specifics about myself in publications. Findings in Chapter 3 around disclosure show the consequences of certain identity-based disclosures can range from harmless to significant. I myself do not enjoy opening myself up to hate, perhaps because I feel like I have experienced enough when I was around the same age as members of the community advisory board. Instead, I value collective positionality statements that identify values, biases, discussions about power dynamics, and identity-based disclosures, if relevant and with consent from everyone involved.

Allyship: The last tension pulls from lessons across the previous three to propose an allyship-oriented approach to doing research with marginalized people in HCI. I view my work as allyship-aspirational, meaning that I would not label the work nor myself as allyship but values of justice, leveraging power structures, and liberation are embedded across this dissertation. My methods in this dissertation work towards redistributing power as I have engaged with trans and queer youth as partners in the design process. In addition, part of my own allyship-oriented HCI research praxis addresses multiple levels of domination and sites for resistance (Collins, 1990). Primarily thinking about community-levels of influence, the benefit of bringing trans and queer youth together at this specific moment in trans history holds more value than ever. Establishing relationships and a sense of belonging across the community advisory board and future engagements with trans and queer youth is a priority that will shape my methods to come.

Furthermore, my own understanding of allyship takes into consideration several critiques. Proposing instead the model of an accomplice, activist organizations have pointed out that allyship has been taken up for selfish purposes. They point out that rather than promoting the needs and priorities of marginalized people, allies commonly put themselves first. Sponsorship is an additional spin on allyship, highlighting active advocacy. Chow outlines several tenets of sponsorship: amplifying, boosting, connecting, and defending (Chow, 2021). I incorporate these criticisms of allyship to distinguish from a performative allyship done for purely self-serving reasons. To do so, I have established infrastructures for participants to validate data, alter the course of the methods, and give feedback on hopeful benefits of participation. In my experience with the QTAB, for example, I am in constant dialogue with members to ensure that there is agreement about the direction of the project and our co-design work.

These tensions are not a checklist where completion of each step and every consideration guarantees equity in HCI. Despite my efforts, I have not extinguished exploitation in my practices completely, because as I argue in Chapter 3, all four tensions of exploitation, membership, disclosure, and allyship are inherent to HCI research with marginalized people. Regarding exploitation, researchers cannot ever know for certain if their attempts to achieve more parity in research experiences for marginalized people is successful. Future work focusing on these experiences is necessary to develop more effective research techniques for equitable and inclusive design partnerships. Additional work is needed to guide researchers in reflecting upon their own membership and disclosure practices and expectations. This form of introspective work is not as simple as it seems, particularly in an academic field that prides itself on solutionism. Shifting towards a paradigm that embraces the convoluted mess associated with mixing social identities with research can work towards a culture of equity in HCI research.

6.2 Commitments in Designing Trans and Queer Health Equity Technologies

Information scholar Oliver Haimson and colleagues have previously described trans technologies as systems that support values of temporality, openness, change separation, realness, intersectionality, and erotics (Haimson et al., 2021). These themes play out in technologies to support aspects specific to the trans experience. For instance, Haimson et al. write that in their earliest instantiations, homepages were "*highly malleable (due to HTML),* *allowing users to delete and remake sites as their identities and genders shifted*" (Haimson et al., 2021). They additional discuss the connection between intersectionality and erotics and their representational importance, calling for trans technologies to include policies and economic models that support erotic content (Haimson et al., 2021). Defining the phrase, Haimson describes that "*a trans technology must embrace the materiality, multiplicity, fluidity, and ambiguity that lie at the heart of transgender experiences*" (Haimson et al., 2021).

This dissertation's focus on Project OISET falls under the category of trans technology in that the sex education resource manifests the values that Haimson and colleagues identify, is led by community partnerships with trans young people, and addresses trans people's various and unique health needs. Taking inspiration from these values in trans based technology design and commitments outlined in the Intersectionality Research for Transgender Health Justice Framework, I argue that designing trans and queer health equity technologies should involve the following commitments: a commitment to inclusion, a commitment to privacy and security, a commitment to systems thinking, a commitment to reflexivity and positionality, and a commitment to impact. These commitments serve to hold designers and researchers accountable in the pursuit of justice for trans and queer people.

6.2.1 Committing to Intersectional Inclusion

Aligned with the third action towards trans health justice of centering embodied knowledge (Wesp et al., 2019), inclusion was a theme that spans this entire dissertation especially as it relates to equity both in the development of the OISET technological artifact and in research methods. Design-based findings in Chapter 4 demonstrated the importance of creating inclusive online experiences for users no matter their identity, experience, or conditions as well as the consequences of failing to account for the diversity of what it means to be trans. As participants in that study highlighted, a poor or singular framing of the trans experience can unintentionally invalidate the identities of those who fall outside of what is represented. In relation to privacy and security in Chapter 5, inclusion came out through the personalization of user settings, which controlled everything from how data are stored, managed, and deleted to the platform's aesthetic. As those we engaged with in this study pointed out, ensuring that trans youth can determine their online experience themselves is crucial to protecting them. Discussions with QTAB members explored whether it was possible to have too much control over one's data and how this might overwhelm users or instill a sense of fear. However, we identified that users deserve to have the tools and information they need to make informed decisions. Whether they want to access the privacy and security settings, for instance, should be left up to the user to decide, but the platform's design can at the very least inform the user that that is available for them to use at any time. Having agency in this way also nods towards the value of separation in trans technologies (Haimson et al., 2021). The authors reference how Tumblr users could divide their online audiences in a way that made them more comfortable being themselves, enabling freedom of expression and identity exploration.

Appreciating inclusion in research methods necessitates participatory engagements with people who are directly affected by the research topic. As a principle, inclusive research practices evokes the notion of "Nothing About Us Without Us" that has emerged from critical scholarship around Disability Studies and sex work (Charlton, 1998; Healthwrights, 1998; Best Practices Policy Project And Desiree Alliance, 2010). As Haimson and colleagues advocate for, involving trans people and communities is necessary for designing trans technologies (Haimson et al., 2023).

Working towards *intersectional* inclusion requires more intentional steps of involvement. It is not simply a checklist item nor a post-hoc consideration, but an active operation that goes beyond theorization towards praxis (Collins & Bilge, 2020; Rankin & Thomas, 2019). Being intentional about intersectional inclusion in research methods extends across a number of practices, from how data are collected and presented in publications (Ruberg & Ruelos, 2020; Chen et al., 2023) to attend to participants' various needs to engage in research (e.g., safe access to bathrooms, transportation to and from study site). However, I have witnessed two obstacles when pursuing methodological intersectionality. First, when working to navigate diverse needs, researchers also must be prepared to handle situations where participants have different requirements. To address this, researchers can work with participants to understand how everyone might work through these conflicts together. For instance, one standout interaction happened in one of Chapter 4's focus groups where one participant who was older was unsure of how much detail to share about their sexual health experiences because they wanted to be considerate of the younger people in the room. After they asked the research team what to do, we opened that question up for the room to discuss, intentionally so that we could negotiate our collective boundaries *together*, instead of simply having the researchers dictate what to do and how to behave. There is additional difficulty in conceptualizing intersectionality as an operation where the whole is greater than the sum of its parts. While it can be easy to fall into traps of adding up single axes of privilege and/or oppression, scholars have called for HCI research to go beyond individual user identities and instead attend to "interacting processes" of people's experiences (Schlesinger et al., 2017; Wong-Villacres et al., 2018).

Keeping in line with the participatory ethos of this dissertation, I argue that a key part of attending to intersectionality is through participation and understanding nuances of people's lived experience. This approach specifically works to counter any notions that participants' experiences can be understood as individual pieces of identity. As I have witnessed, enacting participatory values with a diverse set of participants, much like the community advisory board that has supported Project OISET, holds researchers accountable to intersectional methodological decisions and analyses, pushing the work forward to greater levels of equity and inclusion.

6.2.2 Committing to Privacy and Security

Chapter 5's focus on privacy and security clarified intersections with design, but my reflections on working with trans and queer youth through the QTAB also demonstrate the researcher's role in maintaining protections. Harkening back to the value of separation in designing trans technologies, intentionally designed privacy and security settings allow users to manage who has access to what information (Haimson et al., 2021). As a result, users may feel more freedom to be themselves. Current design trends rely upon education and ad-hoc mechanisms like a quick exit button, but a queer privacy-by-design orientation to designing safe online experiences calls for designers to create better protections by default so that harm does not even take place at all.

Researchers must additionally work to maintain privacy and security of those who are involved in studies. In my own coordination of the QTAB and those who have participated in the studies that form this dissertation, I utilized member-checking, anonymity, and data deletion after a study was completed. In Chapter 3, due to the close-knit nature of HCI researcher circles, participants raised concerns about being identified through their data. For instance, there are only a handful of out non-binary HCI researchers, and so participants discussing this aspect of their identity could be discovered and face repercussions. I made use of member-checking throughout the study in Chapter 3 by relaying how I interpreted and presented data in the manuscript to their respective participants. In most cases, participants engaged in member checking by confirming how their data were represented but some also made clarifications to my analysis, which helped strengthen the overall argument.

Given this dissertation's focus on justice and equity for both trans and queer people and those who experience systematic oppression, foregrounding privacy and security in both design and research praxis has been a vital lesson. Previous work has linked privacy protections to social justice movements such as grassroots movement building and protest organizers (Hirsch & Henry, 2005; Ghoshal & Bruckman, 2019). As Ghoshal and Bruckman reveal, privacy is necessary for collective action because people must feel secure enough to engage in democratic participation (Ghoshal & Bruckman, 2019). In this way, privacy and security protections must be baked into a greater infrastructure of care (Tseng et al., 2022). The queer privacy-by-design framework presented in Chapter 5 provides headway into how technology designers might preemptively account for threats and harms for trans and queer users.

6.2.3 Committing to Systems Thinking for Health Equity

Across the studies presented in this dissertation, each investigation revealed connections to a broader ecosystem of needs and power dynamics. To this end, systems thinking is a particular framework that helps clarify and conceptualize such systems as networks of power and levers for social change, referring to a system as an organization of interconnected elements that ultimately achieves something (Meadows, 2008; Stroh, 2015). Systems-level thinking, then, is made up of several elements: it prioritizes long-term efficacy over short-term fixes; understands that solutions are complex and not always directly connected to their problems; identifies that we have the power to change the elements of the system; invests in the relationships between parts of the system; and adapts to complex sets of stakeholders, obstacles, and conditions. As opposed to a binaristic perspective, systems-thinking embraces messiness towards solutions that are more effective, sustainable, and, I would argue, human-centered.

In this dissertation, I have explored how a systems-level approach can more effectively address the health needs of queer and trans youth. My work on OISET (chapter 3) and trans and queer youth's privacy needs and environment (chapter 4) show how technical artifacts are often overcoming systems-challenges, such as the design of school based curricula or other artifacts as well as laws that undermine youth privacy. Chapter 3 additionally examines HCI research involving marginalized people through a broad theoretical perspective, like Collin's matrix of domination (Collins, 1990). In particular, the study's third sub-research question focused on HCI's field-level norms affect on researcher behavior and participant experience is representative of the holistic stance necessary to more deeply understand why systematic oppression occurs. A systems-level approach has led me to envision pathways forward beyond just technological solutions. For instance, in Chapter 4 we advocate for policy changes for inclusive, gender-affirming sex education curricula for all students and discuss the disadvantages of privacy blockers implemented in school computers.

Drawing from Collin's theory of systematic oppression also elucidates possible sites for resistance, specifically around three levels: the individual, communal, and structural (Collins, 1990). Drawing from a public health metaphor, designing and implementing *upstream* interventions means to address more widespread conditions, rather than solely focusing on changing individual behaviors. Veinot et al. outline how addressing communal and structural contexts leads to more equity in health experiences (Veinot et al., 2019). Previous work has shown that interventions that prioritize individual behavior and psychosocial changes can reinforce health disparities because they are less effective for marginalized people (Boelsen-Robinson et al., 2015; Hillier-Brown et al., 2014). Wesp et al.'s Intersectionality Research for Trans Health Justice Framework similarly connects power imbalances stemming from oppressive structures, institutional systems, and socio-structural processes to trans health inequities (Wesp et al., 2019). The framework also calls for a commitment to naming intersecting power relations by identifying the specific structural forces across all three layers of the framework and how they operate to create experiences of privilege and/or oppression (Wesp et al., 2019). In the context of Project OISET, I have identified that cisheteronormativity, racism, ableism, capitalism, and more unite to lead to negative health consequences as well as unfeasible technological interventions for trans and queer people. These systems affect both trans people's experiences with health and researcher and designer biases that can actually reinforce health inequities, rather than repair them (Veinot et al., 2018).

Given the importance of addressing upstream conditions that determine health disparities, collaboration with communities is an effective way of identifying needs and priorities for intervention. As an example, Haimson et al. led participatory workshops with trans communities to outline four types of technologies that support trans people's needs, which include technologies for changing bodies, technologies for changing appearances / gender expressions, technologies for safety, and technologies for finding resources (Haimson et al., 2020). The authors underscore the importance of community-based partnerships, "many of these technologies looked beyond individual solutions to involve other community members, signaling a need to focus on community when designing for trans populations. We advocate for a community-based intersectional approach to designing trans technologies to impact positive change for trans people" (Haimson et al., 2020, pg 10).

As such, a commitment to systems thinking when designing trans and queer health equity technologies involves a holistic, intersectional approach to intervention design, integration of community collaborations, and focus on the upstream conditions that affect health disparities.

6.2.4 Committing to Reflexivity and Positionality

In Chapter 3, I discuss the contours and complexities of reflexive and positionality practices in HCI research with marginalized people. In line with previous scholars who have written about involving marginalized people in research, engaging in reflexivity and positionality is not only ethical but it also produces better science (Bardzell & Bardzell, 2011, p. 678). Reflexivity and positionality are also influential in addressing intersectional trans health justice, shown through the framework's last commitment to disrupt the status quo through self-reflexivity (Wesp et al., 2019).

HCI research has seen an evolution in what the field means when people call for reflexivity. Bardzell and Bardzell name researcher/practitioner self-disclosure and reflexivity as part of their feminist HCI methodology, Schlesinger et al. recommend author disclosure as part of their Intersectional HCI, and Erete et al. include self-reflection as part of their intersectional approach (Bardzell and Bardzell, 2011; Schlesinger et al., 2017; Erete et al., 2018). While the practice is gaining popularity, this dissertation makes the case that engaging in reflexivity and positionality is complicated and often uncomfortable. Sweet captures this well by writing that "questions of reflexivity ask us to consider who we should listen to and why, how to place actors' ideas in a larger field of power, questions about our own relationship to actors' theories of the world. Reflexivity asks us to approach our work with epistemological unease because we are always at risk of reproducing categories that reify power" (Sweet, 2020, pg 924). As I have witnessed and experienced, navigating this "epistemological unease" is an experience filled with self-doubt. As

HCI researchers move towards engaging in reflexivity and positionality on a wider scale, it is important to clarify the messy and psychological nature of this experience. A commitment to this practice, however, provides another step towards achieving equity and justice in HCI researchers' methods and the knowledge and artifacts that follow.

6.2.5 Committing to Positive Impact

People who take part in research, especially for those who have marginalized identities, deserve to not experience harm through their participation and to experience the benefits that researchers promise them. In Chapter 3, I discussed how exploitative research practices create unfair consequences for participants, which led to ethical considerations in Project OISET to mitigate trans and queer youths' potential risk of participation. For instance, I deleted all data traces including the discord servers after the ARC component in Chapter 4 was completed. For the trans and queer youth I have worked with across these studies, maintaining their privacy has been a large priority to avoid potential harm of being nonconsensually identified. As discussed in the section above, reflexivity and positionality is one way to steer researchers away from any potential negative outcomes and risks in their work, though doing so will not necessarily guarantee a study is ethically spotless.

Despite the importance of addressing risks and harms that participants face, this dissertation makes the case that researchers and reviewers must avoid deficit thinking that is solely concerned with potential harms. In considering the impact on participants, researchers should think beyond just mitigating exploitation and towards strengthening what might already exist while still centering equity and justice. This kind of mindset shift can then counteract common research narratives that people that researchers are designing for are vulnerable (Vines et al., 2014; Waycott et al., 2015). Moving away from viewing design and computing interventions through a savior complex, as discussed in Chapter 3, can help HCI researchers refocus on whether the systems that we are building meet actual human needs or have meaningful impact on people we are designing for. In this reframe, designers are not overtly powerful beings who can alter oppressive conditions as their will; instead, they are another component in a greater liberatory system.

Previous HCI scholarship has highlighted the rewards of an assets-based approach (Wong-Villacres et al., 2020; Wong-Villacres et al., 2021; Wong-Villacres et al., 2022). In a reflection across two assets-based research contexts, Wong-Villacres and Gautam identified their own commitments to enacting this kind of work including infrastructuring trust-building throughout a study’s method, establishing an interdependent collective among participants, and taking smaller, incremental steps forward (Wong-Villacres et al., 2021). The authors then discussed the value of evaluating assets prior to design work, rethinking the role that technology plays as an intermediary rather than an endpoint, and “embrace impact in the shape of slow incremental transformation” (Wong-Villacres et al., 2021, pg 1). Grounded in my experience with Project OISET, integrating community-based participatory research values can complement this assets-based approach. Similar to the contributions from Wong-Villacres and Gautam, Cooper et al. have recommended greater involvement of communities in the formation of a research problem and vision statement (Cooper et al., 2022). Both sets of authors suggest reconsidering when in a study researchers consider participants’ needs and strengths (i.e., before intervention versus after intervention) so that outcomes of research are more human-centered and thus more impactful.

Additionally, in order to have a deeply felt impact, systems design also does not always have to equate to technological intervention. The design of inclusive policies, for example, are a component of challenging inequities caused by inadequate sex education, and I am encouraged by efforts like Washington state's Referendum 90 that requires public schools to provide age-appropriate, inclusive, and comprehensive sexual health education. However, while it is encouraging that more states are designing better sex ed experiences, these efforts are still unavailable to a large number of youth across the US and the world. With an increasing number of states actively removing trans people's access to healthcare, there is still much work to be done and that liberation must be achieved for all, not just any one group.

Finally, in Chapter 3, I explored the question of how HCI's norms as a field contribute to exploitative research practices and outcomes for participants. Following this inquiry, I call for a greater examination of how HCI conceptualizes and evaluates impact, particularly for marginalized people. Part of this involves researchers taking greater responsibility in their role as catalysts in systems of oppression, possibly through reflexivity and positionality. To this point, Lett and colleagues warn against "health equity tourism" in which researchers who are new to health equity research swoop into these contexts without proper preparation or knowledge (Lett et al., 2022). They identify two consequences of health equity tourism: pollution, in which tourists "mischaracterize root causes of health inequities and obfuscate potential solutions" and dilution where too many proposals and interventions can hinder decision making (Lett et al., 2022, pg 2). These concepts extend into HCI research involving health equity, especially as researchers continue to seek out community partners. Lett and their coauthors establish four value principles for researchers: equity, positionality, collaboration, and sustainability. Across these efforts, HCI researchers need to be more intentional about how we design for social change.

6.2.6 Committing to Deconstruction in Systems Design

Deconstruction is a theoretical practice close to the heart of Queer Theory, emerging directly from a Foucauldian genealogical analysis of power (Foucault, 1990). In a turn towards embracing multiple ways of knowing, viewing, and experiencing the world, it works to identify how people's assumptions can be harmful and unnecessary—as is the case when thinking about gender as a man/woman binary. As Nikki Sullivan writes, deconstruction "enables us also to ask why it is that in particular cultural contexts being is divided up in this (arbitrary) way, and who it is that benefits from the cultural logic that (re)produces these kinds of divisions" (Sullivan, 2003, p 51). In brief, deconstructing is a process that involves understanding the significance of a concept's historical and cultural meaning. This discovery process provides an opportunity to challenge social and political hierarchies, understand the complexity of people's lived experiences with both privilege and oppression, and find alternative paths of thinking and living (Sullivan, 2003).

I applied this analytical orientation towards social power throughout this dissertation research, specifically in the ways that I have worked to both recognize and open up assumptions I carry as a researcher. For example, my initial approach to the study in Chapter 3 was heavily focused on allyship, but upon review of our findings, I realized how allyship could only account for a subset of the data. Had I been singularly concentrated on allyship, I would have missed the rich themes that led to the formation of the additional tensions. I also have found that participatory methods are a valuable tool in intercepting assumptions and biases. In my involvement in Project OISET, I have held many assumptions about working with youth, and verifying with the trans and queer youth I have worked with so far has confirmed, overwritten, and furthered my understanding of their needs and experiences.

Deconstruction also echoes previous calls to action toward liberation from oppressive structures. For instance, Harrington et al. demonstrate how an “analysis of the historical context of the research” led to a deeper understanding of research injustices their participatory design workshop participants have witnessed. This knowledge then allowed the research team to make more informed choices regarding gaining access to this group of people, how to structure study materials and activities, and potential barriers that might hinder participants from sharing their authentic stories (Harrington et al., 2019). Erete et al. extend this idea further by outlining *intersectional analysis of power* as “a method that enables HCI researchers, designers, and practitioners to identify and situate saturated sites of violence in a historical context and to transform the ways in which they engage with populations that have been historically oppressed” (Erete et al., 2023). This concept draws from a lineage of Black feminist thought and intersectionality scholarship. The authors carry out this approach by identifying sites of historical and extant violence; intersecting power networks at play; how hierarchies are upheld and through what assumptions; the effects of subjugation and oppression on Black people; and paths for resistance (Erete et al., 2023). Deconstruction also harkens to a commitment of naming intersecting power relations outlined in the Intersectionality Research for Transgender Health Justice (IRTHJ) Framework. As these examples advocate for, designing systems that intervene power hierarchies should involve, first, establishing a deep understanding of situated histories and cultures and, second, methodological adjustments that respond to these ramifications and disrupt the harmful cycles of oppression.

In my own exercise in reflexivity and positionality, I have witnessed the rewards that come with a queer outlook on systems design of health technologies. Within deconstruction, there exists a particular orientation towards openness, freedom, and joy that make up queerness more wholly. To this end, poet Ocean Vuong offers this stark portrayal, writing “queerness in a way saved my life [...] Often we see queerness as a deprivation, but when I look at my life, I saw that queerness demanded an alternative innovation from me, I had to make alternative routes. It made me curious, it made me ask this is not enough for me because there's nothing here for me." Vuong builds off common narratives that frame queerness as a source of pain by outlining how it also leads to demanding for oneself more and better and creating divergent paths towards happiness and success. Framing queerness as a catalyst like this resembles an approach to design and engineering for social change and destabilizing structural oppression. Previous work has explored the connection between queerness and design to provide lessons and opportunities for the development of future health technologies. Researchers have demonstrated the deconstructive principle of identifying and reassigning meaning behind specific assumptions when going through the design process. For instance, Green further provides an example of how to reframe assumptions by reconsidering resistance when working with participants as a productive interaction, rather than a detraction (Green, 2021). Denz and Eggink further call out the need to avoid assumptions about who the participant is, particularly their gender, pronouns, and how they want to be treated (Denz & Eggink, 2019). Through a review of queer health platforms, Beare and Stone call out design principles of centering queerness, amplifying lived experiences, and focusing "less on individual access to care and more on community support and celebration" (Beare & Stone, 2021, pg 1). Further work has both reworked existing technology to adapt to queer and trans needs (e.g., refitting Apple Face ID algorithms to detect different faces of the same person) and new technologies as well, such as a wearable device for protecting trans users' safety (Starks et al., 2019; Baeza Argüello et al., 2021).

Queerness has so much to offer systems design including important values for meeting the needs of trans and queer users and the process of how we build technologies with people.

Deconstruction holds researchers accountable for our preconceived notions and provides a tool for ensuring that a researchers' bias does not end up punishing others. Embedded in this idea is that research and design are not objective, neutral processes, but instead political in nature with potential for liberation. Through this dissertation, I offer ways that queerness can benefit technology design and conversely what technology design can offer queerness. With an engineering approach comes a culture of taking action through iterative making, break, and testing. This constant cycle of refinement can help provide systems that are highly equipped to support people's needs. Queerness, then, offers vital considerations for equity and care through both the outcomes of design work and the process of engaging with people to develop technologies. Combining these two forces together can lead to a future of health technology design that delivers human-centered experiences without compromising the needs and well-being of the very people these systems are meant to serve.

6.3 Reflection on Methods

As a key part of this dissertation's claims, I call for adjustments to HCI methods that better suit the needs of queer and trans people. In this section, I reflect upon two methods I have used throughout this work—ARC and co-designing with a community advisory board—and offer what has worked well and what might be improved in future enactments of these methods.

To resummarize, asynchronous remote communities allow for flexibility in how and when participants contribute towards study activities (MacLeod et al., 2017). Previous work has used this method to engage with populations who are typically hard to reach because of difficulties traveling to physical locations; sociopolitical conditions that discourage large gatherings; or researchers wanting to recruit outside of their local spaces (MacLeod et al., 2017), especially when the researchers seek to engage longitudinally and the barriers to in-person research would compound for each successive interaction. The asynchronous nature of ARCs also supports participants fitting the activities amid their other commitments. These discreet and flexible qualities of the method have lended themselves to working with people living with HIV, people with rare health conditions, and teens dealing with stress and anxiety (Bhattacharya et al., 2019; Maestre et al., 2018; MacLeod et al., 2017). To determine the success of an ARC, previous literature has outlined specific elements that include successful recruitment, data collection, and engagement with study activities (Maestre et al., 2018).

In Study 4, I used an ARC to engage with trans and queer youth in between in-person study components. In the following study, I assembled and partnered with a community advisory board, known as the Queer Trans Advisory Board (QTAB), to co-design the future OISET. This QTAB communicates through Discord, an online platform that many of the trans and queer youth advocated for because they were already Discord users. The QTAB's organization and engagement worked as an extension of the ARC method, especially considering Maestre et al.'s formal definition of an ARC. For instance, QTAB members met synchronously each month with additional asynchronous activities and opportunities to contribute outside of concurrent meetings.

There are several elements that make the particular instantiation of ARCs in Studies 4 and 5 distinct from previous work, offering further lessons for engagement with marginalized people in HCI. First, both studies integrated synchronous and asynchronous activities. Previous work has introduced synchronous components to an ARC, such as remote interviews (Prabhakar et al., 2017), but there is little work that has combined co-design with traditional ARC activities in the ways that I have in this work. Bringing these two methods together comes with advantages and drawbacks. For example, study members are able to connect with each other when engaging in activities synchronously, which can then improve how they work together asynchronously. In

Study 4, despite all being from the greater Seattle area, trans and queer youth participants' enthusiasm for meeting other trans and queer youth was clear, and many participants brought up how this was the first time they had been in a room full of others like them. Following these in-person focus groups, I noticed how online discussions in the ARC portion of the study were lively and participants engaged with each others' ideas. When it comes to determining success of an ARC, previous work has focused on engagement with study activities, but there should be more attention placed on the connection among ARC members. Future work is needed, however, to validate whether combining synchronous and asynchronous activities with the same group of study participants leads to greater engagement among the group.

Shifting towards a success metric focused on engagement among ARC members can be particularly beneficial for people living through ongoing social, political, and legal strife, like trans and queer youth. While few examples of engaging in ARCs amidst changing sociopolitical conditions exist, one previous study focused on how parents manage their technology use in their family lives during COVID-19 in the United States (Michelson et al., 2021). In this work, QTAB activities have and continue to coincide with a dynamic, damaging climate when it comes to trans and queer young people due to the introduction and passing of bills that ban access to trans healthcare. QTAB members have come together for support through this time of uncertainty, fear, and anxiety. As specific bills have been introduced and passed through various government bodies, individual QTAB members in those states have voiced their concerns about their ability to remain where they are. One QTAB member felt stuck, as they wanted to move to a state with more inclusive laws but were inhibited by the cost of moving their family, which would involve a costly breaking of their lease agreement as well as time and energy that they did not have. In a Discord post, this member expressed their worries and fellow QTAB members jumped in to offer their support. One member volunteered to review their lease agreement to determine how much it would cost to break their contract. Others extended affirmations and concern for their well-being. I made efforts to set up a GoFundMe to collect funds that would enable them to move if needed. This display of communal, on-demand support has been a powerful suggestion of what ARCs can accomplish for populations that are actively being targeted.

While traditional participatory design approaches emphasize relationships developed between participants and researchers, I align myself with previous scholarship that explores relationality more holistically (Pihkala & Karasti, 2018; Simonsen et al., 2019; Udoewa, 2022). The acts of support and solidarity I have witnessed working with the QTAB represent the radical reframe of relationality made possible through this method. However, future work is needed to better understand the QTAB members' experience with the felt effects of such communal support. Queer and trans relationality provides a window into understanding how social networks established through the methods I have used in this dissertation operate. Tied closely to trans relationality, which LeMaster refers to as “queer bonds that enact queer worlds through exploring the dialectic tension between the individual and the institutional”, the relationships within the QTAB are both socially informed and constructed (LeMaster, 2017). As a result, these bonds that QTAB members and I have built together simultaneously challenge the cisheteronormative norms pressed down upon us and reveal paths forward.

While there have been added benefits of the participatory methods used throughout this dissertation, I have also encountered various barriers to engaging with trans and queer youth as design partners in a meaningful way. For instance, while it has been fortunate for QTAB members to be able to support each other, the present danger of anti-trans legislation has hindered the group’s ability to connect with each other and participate in research. On top of working through the latent stress of surviving this period of strife, QTAB members are having to navigate changing, hostile environments at their schools, in their homes, and where they live, making participation in study activities less of a priority. In addition, the Institutional Review Board (IRB) that we have been working with has created barriers to the kinds of partnerships that I am hoping to develop with the members of the QTAB. The IRB is right to ask what heightened protections are necessary for working with trans and queer minors in research, they must also do so in ways that recognize that these youth can be partners in the research and who have their own agency and goals. The IRB acts as an overall protective framework, but I have experienced how such a system is ill-equipped to adapt to the dynamic conditions and needs of action-oriented research with trans and queer youth today. The slowness of moving through the IRB's bureaucracy and being left in limbo for over a year has inhibited my ability to meaningfully support trans and queer youth. In particular, I argued against classifying QTAB members as traditional study participants because of how this categorization would undermine the kind of relationship I hope to develop with them, as design partners. Casting QTAB members as study participants reinforces a paradigm of doing research on them, rather than with them, and I argued that it is possible to follow informed consent protocols, mitigate risks of participation, and protect QTAB members from outside harm without an official designation as research participants. Here, the IRB has defaulted to its view of seeing QTAB members as children, needing additional protections in 45 CFR 46 part D, rather than seeing the full context of their experiences: trans and queer youth who are being legally targeted, may lack supportive loved ones, and are seeking to partner in research that can build a better future for other youth like them.

A final reflection on our methods returns to the upstream to downstream levels of interventions for health equity modeled by Veinot and colleagues (Veinot et al., 2019). The lessons about how to design an OISET for and with trans and queer youth connect to multiple levels along this intervention spectrum. For instance, the OISET sets out to meet individual-level sexual health needs by providing sex education information. The OISET also strives towards more upstream levels of intervention as well, towards communal support, relationship development, and navigating discriminatory social policies. As this demonstrates, systems design should work to strike a balance of levels of interventions, rather than solely focused on one end or the other. As long as upstream oppression exists, there is a need for downstream interventions.

6.4 Future Work

Queer Theory has played a pivotal role throughout my approach to the work presented in this dissertation. For instance, I have applied the two principles of Queer Theory I outlined in Section 2.4.1, challenging and expanding norms and promoting personal autonomy towards liberation, towards my methods. Challenging and expanding norms has led me to scale up my analytical lens to reconsider traditional researcher-participant roles in multiple directions: within, by rebalancing power dynamics, and beyond, towards researcher-researcher interactions and the effects of field-level HCI norms. Using the ARC method in the research described in Chapters 4 and 5 has been a direct result of expanding norms of participation in HCI research, shifting towards a method of involvement that caters towards participants' needs, schedules, and priorities. Furthermore, I have taken the principle of promoting personal autonomy towards liberation into my personal analytical framework. This liberatory stance has informed my diligence towards upstream structures and systems that result in health inequities for queer and trans people, while also understanding that on an individual level, people must navigate numerous experiential permutations that call for personalization in research approaches and design futures.

There are also many ways that I have been less intentional about applying Queer Theory to make decisions, leading to limitations in this work. In reviewing this work retrospectively, I consider the unique contributions that Queer Theory adds complexity to my analysis for future considerations in work to come. First, I have reflected upon my interchangeable usage of the terms queer, trans, and marginalized and recognize the lost nuance in doing so. These terms share a tension of demarcating people's specific experiences with marginalization and privilege, but my usage of the terms can also frame them as people's sole experience. Queer Theory offers a way to see both/and, rather than an either/or. I have additionally found difficulty in fully adhering to values of democratizing participation in research. In my experience with the QTAB, I have sought to create a decentralized leadership structure that provides checks and balances to who holds power in decision-making. However, QTAB members are busy and have their own lives and priorities to attend to, meaning they have less time and capacity to take on the responsibilities we would ideally share. As a result, I have taken up a larger leadership role than I had hoped to, but I will continue to look for space to share decision making and give QTAB members room to disagree and redirect the group's direction. Finally, future work should examine how participatory engagements with trans and queer youth like the QTAB modify the construction of the queer child. Considering trans and queer youths' current politically targeted status, there is much to learn about how methods can reconstruct dominant narratives that frame trans and queer youth as threats to the State and hegemonic ideologies. Reinstating power back into the hands of trans and queer youth over the design of their future worlds can provide opportunities for liberation for all. Reflecting over these limitations, future work will incorporate queer theory as well as further explore the cannon's inherent tensions between ideal and practical applications.

Furthermore, much of this previous section's focus on impact hinges upon participants' experiences; however, there are few mechanisms that give researchers this kind of insight. HCI researchers lack understanding of how realistic, useful, or even damaging design methods and interventions are for participants. To this point, Harrington et al. raised concern around blue-sky ideation design methods by pointing out that not all participants might enjoy this kind of idealistic futuring exercise (Harrington et al., 2019). Hirsch further examined the ethical concerns of using qualitative methods to discuss sensitive topics with research participants and called for more trauma-informed methods (Hirsch, 2020). Additional research is needed to better understand participant experiences in HCI research, especially in cases where equity and justice are priorities. This future work can build off existing member-checking techniques to verify not just results from data analysis but also whether or not a study's methods properly took into account a participants' lived experience and additional impact-focused dimensions.

Building from the Project OISET studies in this dissertation, future work will be focused upon the transferability of findings, extending the analytical connection from the four tensions identified in Chapter 3 to Project OISET I have demonstrated throughout this dissertation. Transferability is held together by the belief that one cannot always assume that the results from one research study will uniformly hold up in another, which makes it distinct from the concept of generalizability. In health intervention contexts, researchers can seek out the transferability of the outcome and/or the transferability of the process. To investigate this, future work might take lessons from one health equity context and test their applicability in another, leading to the question of how might the lessons about design and process from one health equity context transfer to another?

An additional area for future research based on this dissertation work involves deployment and evaluation of trans health equity technologies such as the one designated in Project OISET. Haimson et al. point out a gap in research where trans equity projects often do not get fully realized to meet the needs they originally set out to accomplish (Haimson et al., 2023). To address this gap, they suggest the following: create programs to bring designs from classrooms and academic research to deployment, match trans tech designers and developers, connect tech creators with community members, and make more space for publishing on technology deployment and user studies (Haimson et al., 2023). As such, the future of Project OISET involves deployment and evaluation by integrating these recommendations. I plan to continue to connect with students, designers, and systems builders across universities, LGBTQ+ tech organizations, and more towards future iterations of the sex education tools we are building with trans and queer youth.

While HCI overall struggles to bring research findings to practice, and research can also fail to notice and incorporate needs and approaches developed in practice (Colusso et al., 2019). However, my experiences show how trans equity projects are further held back by the same structures of oppression and domination that they seek to reform, which manifest in who gets to conduct or participate in trans equity research or in the design and building of sociotechnical systems and are shaped by considerations like funding models and priorities.

With this work in mind, I hope that the future of trans and queer system design embraces equitable and inclusive methods so that trans and queer people can enjoy the benefits of innovation without the tradeoff of surveillance, harm, and additional risks. The current state of trans technologies in particular has so much room for growth, and we are just at the beginning of delivering human centered technological systems that promote not just survival but also joy, connection, and love. Trans and queer people deserve to enjoy the bounty of novelty and innovation without having to fear for their own lives. The future of systems design should not be withheld from trans and queer people, but that gap exists because designers and technologists cannot yet deliver these experiences without compromising safety. Even still, there is an encouraging body of emerging work towards novel systems that are intersectionality inclusive and draw from participatory principles of community-based systems design (e.g., Ovalle et al., 2023).

To get us there, I once again borrow from Collins' Matrix of Oppression to consider how researchers might work towards resistance at communal and structural levels. There is a great need to develop more upstream protections, especially when it comes to systems design. A trans and queer ethics review board that is community-led, financially supportive, and institutionally independent could provide crucial oversight over the future of trans and queer systems development. Studies and designs that focus on trans and queer people might then require the approval of such a review board, much like an Institutional Review Board already acts. Regardless of how we choose to get there, the future trans and queer research must involve trans and queer people.

Chapter 7. Conclusion

Despite the already existing barriers to healthcare that trans and queer people face in the United States today, continued attacks and legislation banning access to gender-affirming care are growing in number. A report from the Williams Institute shows that as of March 2023, 30 states have restricted access to gender-affirming care or are currently considering laws that would do so" (Redfield et al., 2023). Many of these bills additionally punish healthcare providers and family members who assist trans and queer youth in getting gender-affirming care. Initial restrictions sought to remove trans youths' access to healthcare, but more recent bills are being introduced that would limit access to care for trans people up to age 26 (Redfield et al., 2023). One national survey reported that 94% of LGBTQ+ youth "reported that recent politics negatively impacted their mental health" (The Trevor Project, 2021). It simply cannot be overstated; the effects of these bills and the ensuing politically-charged landscape are detrimental to trans and queer young people today.

Engaging in this dissertation work in the leadup to and precipitation of this rise in anti-trans legislation has been both a source of hope and grief. I have been witness to the joyful magic of trans youth coming together to build community and support each other. I have also seen the direct impacts of destructive legislation, forcing people to choose between remaining where they are and fighting for their right to exist or move to a supportive state at great costs. Trans and queer youth deserve the space to explore who they are; live as their true, authentic selves; and be free to enjoy the world around them without fear of being harmed.

My direct experience working with a community of trans and queer youth has had a profound impact on the analytical decisions I have made throughout this dissertation. Most acutely, I have been humbled as a technology designer to understand the shortcomings of systems design in making meaningful change. As I discussed with participants how a future online tool might help their sex education, our conversations pointed to a need for safe environments such as schools, clinics, and libraries where trans and queer young people could be themselves throughout even the mundane events of everyday life. An online sex education tool could only accomplish so much. As I have learned, trans and queer youth still have to go out in the world and face harsh treatment via transphobia, homophobia, racism, and more.

Understanding the limits of technology design has informed my stance on holistic, systems-thinking approaches to co-development and reframed how I think about the impacts of design. While it cannot eradicate the evils of this world, this dissertation is grounded in a vision of hope for trans and queer people and marginalized people more broadly, one that is supported but not reconciled by technology design. Through an exploration into first, the ethical dimensions of engaging with marginalized people in HCI research and second, an in-depth case study of designing a sex education resource for and with trans and queer youth, this dissertation forges a complex understanding of how to design health equity technologies with communities. To achieve this second point, I carried out an exploratory design-needs assessment study to identify key considerations for this future tool, particularly themes around designing for safety and for inclusion. This exploration then informed the following study, which focused on the privacy and security needs of an OISET and distinguished current threats, constraints, mitigation strategies, and design patterns for protecting trans and queer youths' privacy and security. Methodologically, these studies demonstrate how to diffuse power into the process of designing novel systems through participatory design showcased in Chapter 4 and participatory threat-modeling in Chapter 5.

Furthermore, my approach throughout this dissertation draws from the four tensions of exploitation, membership, disclosure, and allyship I developed in Chapter 3 and principles of Community-Based Participatory Design, intersectionality, queer theory, and the human-centered design process. I form theoretical contributions by applying existing frameworks, such as privacy-by-design in Chapter 5, and unearthing opportunities for further refinement to better meet the needs of trans and queer youth. In this way, this dissertation both proposes new frameworks for thinking about marginalization in HCI through the tensions of exploitation, membership, disclosure, and allyship and applies broad theories into the specific context of designing a sex education tool for and with trans and queer youth.

Looking across themes from these studies, my analysis culminates in six commitments for researchers and practitioners invested in co-designing trans health equity technologies around inclusion, privacy and security, systems thinking, reflexivity and positionality, and impact. I additionally provide reflections on how I have enacted the four tensions in Project OISET that include decisions I am proud of and places where I have struggled. By presenting these commitments and reflections, I demonstrate how entanglements with specific considerations in HCI research with marginalized people is a perpetually messy yet powerfully rewarding process.

To achieve this more expansive, sociotechnically-oriented understanding of designing technology for marginalized people, HCI researchers must adapt and tailor our approaches to engagement based on contextual needs and priorities. A key component to this process involves embracing four tensions inherent to HCI research with marginalized people—exploitation, membership, disclosure, and allyship. Assembling the elements across this dissertation of working with these four tensions, building a holistic understanding of needs and experiences, and addressing downstream and upstream interventions will transform the way we design technologies for social good. This dissertation carves out an agenda for future research for marginalized people, grounded in a vision that draws from values of justice, equity, and, all importantly, hope for a better future.

References

A. A. Ahmed. 2018. Trans competent interaction design: A qualitative study on voice, identity, and technology. Interacting with Computers 30, 1 (2018), 53–71. DOI:https://doi.org/10.1093/iwc/iwx018

A. Aguirre. 2000. Women and Minority Faculty in the Academic Workplace: Recruitment, Retention, and Academic Culture. SHE-ERIC Higher Education Report. ERIC Publications. DOI:https://files.eric.ed.gov/fulltext/ED447752.pdf

A. G. Parker, V. Kantroo, H. R. Lee, M. Osornio, M. Sharma, and R. E. Grinter. 2012. Health promotion as activism: Building community capacity to effect social change. In Proceedings of the 2012 CHI Conference on Human Factors in Computing Systems. 99–108. DOI:https://doi.org/10.1145/2207676.2207692

A. Gaeta. 2019. Cripping Emotional Labor: A Field Guide. Retrieved from https://disabilityvisibilityproject.com/2019/ 06/03/cripping-emotional-labor-a-field-guide/.

A. Grimes and R. E. Grinter. 2007. Designing persuasion: Health technology for low-income African American communities. In Persuasive Technology (PERSUASIVE'07). Y. de Kort, W. IJsselsteijn, C. Midden, B. Eggen, B. J. Fogg (Eds.), Lecture Notes in Computer Science, Vol. 4744. Springer, Berlin. https://doi.org/10.1007/978-3-540-77006-0_4

A. Iyer and C. W. Leach. 2009. Helping disadvantaged out-groups challenge unjust inequality: The role of groupbased emotions. In The Psychology of Prosocial Behavior: Group Processes, Intergroup Relations, and Helping. WileyBlackwell. https://doi.org/10.1002/9781444307948.ch17

A. K. Brooks and K. Edwards. 2009. Allies in the workplace: Including LGBT in HRD. Advances in Developing Human Resources 11, 1 (2009), 136–149. DOI:https://doi.org/10.1177/1523422308328500

A. L. Hoffmann. 2019. Where fairness fails: data, algorithms, and the limits of antidiscrimination discourse. Information Communication and Society 22, 7 (2019), 900–915. DOI:https://doi.org/10.1080/1369118X.2019.1573912

A. M. Hancock. 2007. When multiplication doesn't equal quick addition: Examining intersectionality as a research paradigm. Perspectives on Politics 5, 1 (2007), 63–79. DOI:https://doi.org/10.1017/S1537592707070065

A. M. Santuzzi, P. R. Waltz, L. M. Finkelstein, and D. E. Rupp. 2014. Invisible disabilities: Unique challenges for employees and organizations. Industrial and Organizational Psychology (2014). DOI:https://doi.org/10.1111/iops.12134

A. N. Antle. 2017. The ethics of doing research with vulnerable populations. Interactions. 24, 6 (2017), 74–77. DOI:https://doi.org/10.1145/3137107

A. Peshkin. 1988. In search of subjectivity—One's own. Educational Researcher 17, 7 (1988), 17–21. DOI:https://doi. org/10.3102/0013189X017007017

A. Quijano. 2000. Coloniality of power and eurocentrism in Latin America. International Sociology 15, 2 (2000), 215– 232. DOI:https://doi.org/10.1177/0268580900015002005

A. Schlesinger, W. K. Edwards, and R. E. Grinter. 2017. Intersectional HCI: Engaging identity through gender, race, and class. In Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems. 5412–5427. DOI::https: //doi.org/10.1145/3025453.3025766

A. Strohmayer, R. Comber, and M. Balaam. 2015. Exploring learning ecologies among people experiencing homelessness. In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems. 2275–2284. DOI:https:// doi.org/10.1145/2702123.2702157

A. Taylor. 2011. Out there. In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems. 685–694. DOI:https://doi.org/10.1145/1978942.1979042

A. To, W. Sweeney, J. Hammer, and G. Kaufman. 2020. "They just don't get it": Towards social technologies for coping with interpersonal racism. Proceedings of the ACM on Human-Computer Interaction 4, CSCW (2020), Article 024, 29 pages. DOI:https://doi.org/10.1145/3392828

A. Vashistha, P. Sethi, and R. Anderson. 2018. BSpeak: An accessible crowdsourcing marketplace for low-income blind people. In Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems. Paper 57, 1–13. DOI:https://doi.org/10.1145/3173574.3173631

A. Vashistha, R. Anderson, A. Garg, and A. A. Raza. 2019. Threats, abuses, flirting, and blackmail: Gender inequity in social media voice forums. In Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems. Paper 72, 1–13. DOI:https://doi.org/10.1145/3290605.3300302

A. Waller. 2020. Nextdoor removes app's 'forward to police' feature. The New York Times. Retrieved from https:// www.nytimes.com/2020/06/23/us/nextdoor-forward-to-police-.html.

A. Ymous, K. Spiel, O. Keyes, R. M. Williams, J. Good, E. Hornecker, and C. L. Bennett. 2020. "I am just terrified of my future": Epistemic violence in disability related technology research. In Proceedings of the Extended Abstracts of the 2020 CHI Conference on Human Factors in Computing Systems. 1–16. DOI:https://doi.org/10.1145/3334480.3381828.

Ahrens, K.R., Spencer, R., Bonnar, M., Coatney, A. and Hall, T. 2016. Qualitative evaluation of historical and relational factors influencing pregnancy and sexually transmitted infection risks in foster youth. Children and Youth Services Review. (2016). DOI:https://doi.org/10.1016/j.childyouth.2015.12.027.

Alkhatib, S., Waycott, J., Buchanan, G., Grobler, M., & Wang, S. (2020, December). Privacy by design in aged care monitoring devices? Well, not quite yet!. In 32nd Australian Conference on Human-Computer Interaction (pp. 492-505).

Anderson, B. (2012). Affect and biopower: towards a politics of life. Transactions of the institute of British geographers, 37(1), 28-43.

Andrzejewski, J., Rasberry, C. N., Mustanski, B., & Steiner, R. J. (2020). Sexual and reproductive health web sites: an analysis of content for sexual and gender minority youth. American Journal of Health Promotion, 34(4), 393-401.

Appenroth M, Davids JD, Feuer C, Kgositau TR, Mugo IN. (2021) No Data No More:

Asad, M. (2019). Prefigurative design as a method for research justice. Proceedings of the ACM on Human-Computer Interaction, 3(CSCW), 1-18.

Ashktorab, Z. and Vitak, J. 2016. Designing cyberbullying mitigation and prevention solutions through participatory design with teenagers. Conference on Human Factors in Computing Systems - Proceedings (2016).

B. A. Israel, C. M. Coombe, R. R. Cheezum, A. J. Schulz, R. J. McGranaghan, R. Lichtenstein, A. G. Reyes, J. Clement, and A. Burris. 2010. Community-based participatory research: A capacity-building approach for policy advocacy aimed at eliminating health disparities. American Journal of Public Health 100, 11 (2010), 2094–2102. DOI:https: //doi.org/10.2105/AJPH.2009.170506

B. A. Israel, E. A. Parker, Z. Rowe, A. Salvatore, M. Minkler, J. López, A. Butz, A. Mosley, L. Coates, G. Lambert, P. A. Potito, B. Brenner, M. Rivera, H. Romero, B. Thompson, G. Coronado, and S. Halstead. 2005. Community-based participatory research: Lessons learned from the centers for children's environmental health and disease prevention research. Environmental Health Perspectives 113, 10 (2005), 1463–1471. DOI:https://doi.org/10.1289/ehp.7675

B. D. Tatum. 1994. Teaching white students about racism: The search for White allies and the restoration of hope. Teachers College Record 95, 4 (1994), 462–476. Retrieved from http://www.goldenbridgesschool.org/uploads/1/9/5/4/19541249/teaching_white_students_about_racism.pdf.

B. de Sousa Santos. 2014. A critique of lazy reason: Against the waste of experience and toward the sociology of absences and the sociology of emergences. In Epistemologies of the South: Justice Against Epistemicide. B. de S. Santos (Ed.), Routledge. https://doi.org/10.4324/9781315634876

B. Lloyd-Jones. 2014. African-American women in the professoriate: Addressing social exclusion and scholarly marginalization through mentoring. Mentoring and Tutoring: Partnership in Learning 22, 4 (2014), 269–283. DOI:https://doi.org/10.1080/13611267.2014.945737

Badge, J. (2021, June 11). How Australia's new proposed Online Safety Bill Targets queer people. Junkee. Retrieved April 5, 2022, from https://junkee.com/online-safety-bill-queer-people/297980

Baeza Argüello, S., Wakkary, R., Andersen, K., & Tomico, O. (2021, June). Exploring the potential of apple face id as a drag, queer and trans technology design tool. In Designing Interactive Systems Conference 2021 (pp. 1654-1667).

Baral SD, Poteat T, Stromdahl S, Wirtz AL, Guadamuz TE, Beyrer C. Worldwide burden of HIV in transgender women: a systematic review and meta-analysis. Lancet Infect Dis. 2013;13(3):214-222.

Bauermeister, J., Choi, S. K., Bruehlman-Senecal, E., Golinkoff, J., Taboada, A., Lavra, J., ... & Haritatos, J. (2022). An Identity-Affirming Web Application to Help Sexual and Gender Minority Youth Cope With Minority Stress: Pilot Randomized Controlled Trial. Journal of Medical Internet Research, 24(8), e39094.

Beare, Z., & Stone, M. (2021, October). By Queer People, For Queer People: FOLX, Plume, and the Promise of Queer UX. In Proceedings of the 39th ACM International Conference on Design of Communication (pp. 20-25).

Benenson, Z., Lenzini, G., Oliveira, D., Parkin, S., & Uebelacker, S. (2015, September). Maybe poor Johnny really cannot encrypt: the case for a complexity theory for usable security. In Proceedings of the 2015 New Security Paradigms Workshop (pp. 85-99).

Benjamin, R. (2020). Race after technology: Abolitionist tools for the new Jim code.

Berlant, L., & Warner, M. (1995). Guest column: What does queer theory teach us about X?. Publications of the Modern Language Association of America, 343-349.

Berlant, L., & Warner, M. (1998). Sex in public. Critical inquiry, 24(2), 547-566.

Best Practices Policy Project And Desiree Alliance. 2010. “Nothing About Us Without Us: The Shared Goals of the Harm Reduction and Sex Worker Rights Movements". Archived from the original on September 20, 2010.

Bhattacharya, A., Liang, C., Zeng, E. Y., Shukla, K., Wong, M. E., Munson, S. A., & Kientz, J. A. (2019, June). Engaging teenagers in asynchronous online groups to design for stress management. In Proceedings of the 18th ACM International Conference on Interaction Design and Children (pp. 26-37).

Black in Computing and Our Allies for Equity and Fairness: 2020. Retrieved from https://blackincomputing.org/.

Black Lives Matter. #TalkAbout Trayvon: A Toolkit for White People. 2017. Retrieved from https://blacklivesmatter. com/wp-content/uploads/2017/10/Toolkit-WhitePpl-Trayvon.pdf.

Bleakley, A., Hennessy, M. and Fishbein, M. 2006. Public opinion on sex education in US schools. Archives of Pediatrics and Adolescent Medicine. (2006). DOI:https://doi.org/10.1001/archpedi.160.11.1151.

Boelsen-Robinson T, Peeters A, Beauchamp A, et al. A systematicreview of the effectiveness of whole-of-community interventions bysocioeconomic position. Obes Rev. 2015;16:806–816.

Booker, A. and Goldman, S. 2016. Participatory Design Research as a Practice for Systemic Repair: Doing Hand-in-Hand Math Research with Families. Cognition and Instruction. (2016). DOI:https://doi.org/10.1080/07370008.2016.1179535.

boyd, d. (2014). It's complicated: The social lives of networked teens. Yale University Press.

Brandt, Allan M. (December 1978). "Racism and Research: The Case of the Tuskegee Syphilis Study". The Hastings Center Report. Garrison, New York: Wiley-Blackwell. 8 (6): 21–29. doi:10.2307/3561468. JSTOR 3561468. PMID 721302. Archived from the original on January 18, 2021. Retrieved May 3, 2023.

Braun, V. and Clarke, V. 2006. Using thematic analysis in psychology. Qualitative Research in Psychology. (2006). DOI:https://doi.org/10.1191/1478088706qp063oa.

Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. Qualitative research in sport, exercise and health, 11(4), 589-597.

Braveman, P. (2006). Health disparities and health equity: concepts and measurement. Annu. Rev. Public Health, 27, 167-194.

Brener ND, Demissie Z, McManus T, Shanklin SL, Queen B, K.L. 2017. School Health Profiles 2016: Characteristics of Health Programs Among Secondary Schools.

Brennan, J., Kuhns, L.M., Johnson, A.K., Belzer, M., Wilson, E.C. and Garofalo, R. 2012. Syndemic theory and HIV-related risk among young transgender women: The role of multiple, co-occurring health problems and social marginalization. American Journal of Public Health.

Brennan, J., Kuhns, L.M., Johnson, A.K., Belzer, M., Wilson, E.C. and Garofalo, R. 2012. Syndemic theory and HIV-related risk among young transgender women: The role of multiple, co-occurring health problems and social marginalization. American Journal of Public Health.

C. A. Le Dantec and W. K. Edwards. 2008. Designs on dignity: Perceptions of technology among the homeless. In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems. 627–636. DOI:https://doi.org/10.1145/ 1357054.1357155

C. A. Le Dantec, R. G. Farrell, J. E. Christensen, M. Bailey, J. B. Ellis, W. A. Kellogg, and W. K. Edwards. 2011. Publics in practice: Ubiquitous computing at a shelter for homeless mothers. In Proceedings of the 2011 SIGCHI Conference on Human Factors in Computing Systems. 1687–1696. DOI: https://doi.org/10.1145/1978942.1979189

C. Cahill. 2007. Including excluded perspectives in participatory action research. Design Studies 28, 3 (2007), 325–340. DOI:https://doi.org/10.1016/j.destud.2007.02.006

C. D'Ignazio and L. F. Klein. 2020. Data Feminism. MIT Press.

C. D'Ignazio, A. Hope, B. Michelson, R. Churchill, and E. Zuckerman. 2016. A feminist HCI approach to designing postpartum technologies: "When I first saw a breast pump I was wondering if it was a joke." In Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems. 2612–2622. DOI:https://doi.org/10.1145/2858036.2858460

C. E. Smith, X. Wang, R. P. Karumur, and H. Zhu. 2018. [Un]breaking news: Design opportunities for enhancing collaboration in scientific media production. In Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems. Paper 381, 1–13. DOI:https://doi.org/10.1145/3173574.3173955

C. Fiesler, S. Morrison, and A. S. Bruckman. 2016. An archive of their own: A case study of feminist HCI and values in design. In Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems. 2574–2585. DOI:https: //doi.org/10.1145/2858036.2858409

C. L. Bennett and D. K. Rosner. 2019. The promise of empathy: Design, disability, and knowing the "other." In Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems. Paper 298, 1–13. DOI: https://doi. org/10.1145/3290605.3300528

C. L. Bennett and O. Keyes. 2019. What is the point of fairness? Disability, AI and the complexity of justice. ACM SIGACCESS Accessibility and Computing 125 (2019), Article 5, 1. DOI:https://doi.org/10.1145/3386296.3386301

C. L. Bennett, E. Brady, and S. M. Branham. 2018. Interdependence as a frame for assistive technology research and design. In Proceedings of the 20th International ACM

SIGACCESS Conference on Computers and Accessibility (ASSETS'18). 161–173. DOI:https://doi.org/10.1145/3234695.3236348

C. Lee and J. Hume-Pratuch. 2013. Let's Talk About Research Participants. Retrieved from http://blog.apastyle.org/ apastyle/2013/08/lets-talk-about-research-participants.html.

C. Munteanu, H. Molyneaux, W. Moncur, M. Romero, S. O'Donnell, and J. Vines. 2015. Situational ethics: Re-thinking approaches to formal ethics requirements for human-computer interaction. In Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems. 105–114. DOI:https://doi.org/10.1145/2702123.2702481

C. N. Harrington and A. M. Piper. 2018. Informing design through sociocultural values: Co-creation with low-income African-American older adults. In Proceedings of the 12th EAI International Conference on Pervasive Computing Technologies for Healthcare (PervasiveHealth'18). 294–298. DOI:https://doi.org/10.1145/3240925.3240966

C. N. Harrington, K. Borgos-Rodriguez, and A. M. Piper. 2019. Engaging low-income African American older adults in health discussions through community-based design workshops. In Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems. Paper 593, 1–15. DOI:https://doi.org/10.1145/3290605.3300823

C. N. Harrington, S. Erete, and A. M. Piper. 2019. Deconstructing community-based collaborative design: Towards more equitable participatory design engagements. Proceedings of the ACM on Human-Computer Interaction 3, CSCW, Article 216 (2019), 25 pages. DOI:https://doi.org/10.1145/3359318

C. Sturm, A. Oh, S. Linxen, J. Abdelnour-Nocera, S. Dray, and K. Reinecke. 2015. How WEIRD is HCI? Extending HCI principles to other countries and cultures. In Proceedings of the 33rd Annual ACM Conference Extended Abstracts on Human Factors in Computing Systems. 2425–2428. DOI:https://doi.org/10.1145/2702613.2702656

C. W. Daum. 2020. Social equity, homonormativity, and equality: An intersectional critique of the administration of marriage equality and opportunities for LGBTQ social justice. Administrative Theory and Praxis 42, 2 (2020), 115–132. DOI:https://doi.org/10.1080/10841806.2019.1659044

Cason, M. 2020. Alabama lawmaker aims to keep transgender athletes off school teams: 2020. https://www.al.com/news/2020/01/alabamalawmaker-aims-to-keep-transgender-athletes-offschool-teams.html.

Cavoukian, A. 2013. Privacy by design: leadership, methods, and results. In European Data Protection: Coming of Age (pp. 175-202). Springer. DOI: https: //doi.org/10.1007/978-94-007-5170-5_8

Chakrapani V, Newman PA, Shunmugam M, Logie CH, Samuel M. Syndemics of depression, alcohol use, and victimisation, and their association with HIV-related sexual risk among men who have sex with men and transgender women in India. Glob Public Health. 2017;12(2):250-265.

Charlton, James I. (1998). Nothing About Us Without Us. University of California Press. ISBN 0-520-22481-7. Retrieved 2010-06-22.

Chen, Y. T., Smith, A. D., Reinecke, K., & To, A. (2023, April). Why, when, and from whom: considerations for collecting and reporting race and ethnicity data in HCI. In Proceedings of the 2023 CHI Conference on Human Factors in Computing Systems (pp. 1-15).

Chow, R. (2021, September 17). Don't just mentor women and people of color. sponsor them. Harvard Business Review. https://hbr.org/2021/06/dont-just-mentor-women-and-people-of-color-sponsor-them

Citron, D. K. (2022). The Fight for Privacy: Protecting Dignity, Identity, and Love in the Digital Age. Chatto & Windus.

Clark H, Babu AS, Wiewel EW, Opoku J, Crepaz N. Diagnosed HIV Infection in Transgender Adults and Adolescents: Results from the National HIV Surveillance System, 2009-2014. AIDS Behav. 2017;21(9):2774-2783. Classroom. University Press of Colorado, Chapter 287-303.

Coenraad, M., Palmer, J., Franklin, D. and Weintrop, D. 2019. Enacting identities: Participatory design as a context for youth to reflect, project, and apply their emerging identities. Proceedings of the 18th ACM International Conference on Interaction Design and Children, IDC 2019 (2019).

Collins, P. H. (1990). Black feminist thought in the matrix of domination. Black feminist thought: Knowledge, consciousness, and the politics of empowerment, 138(1990), 221-238.

Collins, P.H. 2002. Black Feminist Thought: Knowledge, Consciousness, and the Politics of Empowerment. Routledge. DOI:https://doi.org/10.2307/2074808, 557

Colusso, L., Jones, R., Munson, S. A., & Hsieh, G. (2019, May). A translational science model for HCI. In Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems (pp. 1-13).

Combahee River Collective. 1977. Combahee River Collective: A Black Feminist Statement. Let Nobody Turn Us Around: Voices of Resistance, Reform and Renewal; An African American Anthology. Retrieved from https://www. blackpast.org/african-american-history/combahee-river-collective-statement-1977/.

Cooper, N., Horne, T., Hayes, G. R., Heldreth, C., Lahav, M., Holbrook, J., & Wilcox, L. (2022, April). A systematic review and thematic analysis of community-collaborative approaches to computing research. In Proceedings of the 2022 CHI Conference on Human Factors in Computing Systems (pp. 1-18).

Craven, Julia. 2018. “Tumblr Is Betraying The Sex Workers And NSFW Artists Who Relied On The Platform.” Huffington Post. https://www.huffingtonpost.com/entry/tumblr-sex-workers-nsfwartists-lose_us_5c0714fbe4b0fc236111037e

Crenshaw Kimberle. 1989. Demarginalizing the intersection of race and sex: A black feminist critique of antidiscrimination doctrine, feminist theory and antiracist politics. University of Chicago Legal Forum 1989 (1989), Article 8, 139–163. http://chicagounbound.uchicago.edu/uclf/vol1989/iss1/8.

Crosby RA, Salazar LF, Hill B, Mena L. A comparison of HIV-risk behaviors between young black cisgender men who have sex with men and young black transgender women who have sex with men. Int J STD AIDS. 2018:956462417751811.

D. A. Epstein, N. B. Lee, J. H. Kang, E. Agapie, J. Schroeder, L. R. Pina, J. Fogarty, J. A. Kientz, and S. A. Munson. 2017. Examining menstrual tracking to inform the design of personal informatics tools. In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems. 6876–6888. DOI: https://doi.org/10.1145/3025453.3025635

D. Hankerson, A. R. Marshall, J. Booker, H. El Mimouni, I. Walker, and J. A. Rode. 2016. Does technology have race? In Proceedings of the 2016 CHI Conference Extended Abstracts on Human Factors in Computing Systems. 473–486. DOI:https://doi.org/10.1145/2851581.2892578

D. Howard and L. Irani. 2019. Ways of knowing when research subjects care. In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems. Paper 97, 1–16. DOI: https://doi.org/10.1145/3290605.3300327

D. J. Haraway. 2016. Staying with the Trouble. Duke University Press.

D. M. Halperin. 2012. How To Be Gay. Belknap Press.

D’Onofrio, Jeff. 2018. “A Better, More Positive Tumblr.” Tumblr Staff. https://staff.tumblr.com/post/ 180758987165/a-better-more-positive-tumblr

Dank M, Lachman P, Zweig JM, Yahner J. Dating violence experiences of lesbian, gay, bisexual, and transgender youth. J Youth Adolesc. 2014;43(5):846-857.

David M Halperin. 1997. Saint Foucault: Towards a gay hagiography. Oxford Paperbacks.

Dean L, Meyer IH, Robinson K, et al. Lesbian, gay, bisexual, and transgender health: findings and concerns. J Gay Lesbian Med Assoc. 2000;4:102–151. 2.

Delmonaco, D., & Haimson, O. L. (2022). “Nothing that I was specifically looking for”: LGBTQ+ youth and intentional sexual health information seeking. Journal of LGBT Youth, 1-18.

Delmonaco, D., Haimson, O., & Marcu, G. (2020). Community-Based Development of LGBTQ+ Health Information Resources. Specific Populations.

Delmonaco, D., Li, S., Paneda, C., Hughson, L., Popoff, E., Jadwin-Cakmak, L., ... & Haimson, O. (2022). Information Needs for an Online Resource for LGBTQ+ Young People: Mental Health, Sexual Health, and Navigating Services. Currents: Journal of Diversity Scholarship for Social Change, 2(1).

Denz, S., & Eggink, W. (2019, June). Queer-Sensible Designing: Challenging Normative Gender through an Industrial Design Practice. In Academy for Design Innovation Management Conference 2019: Research perspectives in the era of Transformations.

Design Justice Network. 2018. Design Justice Network Principles. Retrieved from https://designjustice.org/read-theprinciples.

Deutsch, M. B., Glidden, D. V., Sevelius, J., Keatley, J., McMahan, V., Guanira, J., ... & Grant, R. M. (2015). HIV pre-exposure prophylaxis in transgender women: a subgroup analysis of the iPrEx trial. The lancet HIV, 2(12), e512-e519.

Dillahunt, T. R., & Lu, A. (2019, May). DreamGigs: designing a tool to empower low-resource job seekers. In Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems (pp. 1-14).

Dillahunt, T. R., Bose, N., Diwan, S., & Chen-Phang, A. (2016, June). Designing for disadvantaged job seekers: Insights from early investigations. In Proceedings of the 2016 ACM Conference on Designing Interactive Systems (pp. 905-910). doi: https://doi.org/10.1177/1049732305276687, accessed 5 September 2020.

Dombrowski, L., Harmon, E., & Fox, S. (2016, June). Social justice-oriented interaction design: Outlining key design strategies and commitments. In Proceedings of the 2016 ACM Conference on Designing Interactive Systems (pp. 656-671).

Dowshen N, Lee S, Franklin J, Castillo M, Barg F. Access to Medical and Mental Health Services Across the HIV Care Continuum Among Young Transgender Women: A Qualitative Study. Transgend Health. 2017;2(1):81-90.

Druin, A. (1999). Cooperative inquiry: Developing new technologies for children with children. Proceedings of the SIGCHI Conference on Human Factors in Computing Systems the CHI Is the Limit - CHI '99, 592–599. https://doi.org/10.1145/302979.303166

E. Brulé and K. Spiel. 2019. Negotiating gender and disability identities in participatory design. In Proceedings of the 9th International Conference on Communities & Technologies—Transforming Communities. 218–227. DOI:https: //doi.org/10.1145/3328320.3328369

E. Lightman, A. Vick, D. Herd, and A. Mitchell. 2009. 'Not disabled enough': Episodic disabilities and the Ontario disability support program. Disability Studies Quarterly 29, 3 (2009). DOI:https://doi.org/10.18061/dsq.v29i3.932

E. M. Broido. 2000. The development of social justice allies during college: A phenomenological investigation. Journal of College Student Development 41, 1 (2000), 3–18. Retrieved from https://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.470.1439&rep=rep1&type=pdf.

E. P. S. Baumer and M. S. Silberman. 2011. When the implication is not to design (technology). In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems. Paper 25, 1–9. DOI:https://doi.org/10.1145/3419249. 3420172

E. P. Williams and J. K. Walter. 2015. When does the amount we pay research participants become “undue influence”? AMA Journal of Ethics 17, 12 (2015), 1116–1121. DOI:10.1001/journalofethics.2015.17.12.ecas2-1512

E. S. Poole and T. Peyton. 2013. Interaction design research with adolescents: Methodological challenges and best practices. In Proceedings of the 12th International Conference on Interaction Design and Children (IDC’13). 211–217. DOI:https://doi.org/10.1145/2485760.2485766

E. Subašić, K. J. Reynolds, and J. C. Turner. 2008. The political solidarity model of social change: Dynamics of self-categorization in intergroup power relations. Personality and Social Psychology Review 12, 4 (2008), 330–342. DOI:https://doi.org/10.1177/1088868308323223

Elia, J.P. and Eliason, M.J. 2010. Dangerous omissions: Abstinence-only-until-marriage schoolbased sexuality education and the betrayal of lgbtq youth. American Journal of Sexuality Education. (2010). DOI:https://doi.org/10.1080/15546121003748848.

Erete, S., Rankin, Y. A., & Thomas, J. O. (2022). A method to the madness: Applying an intersectional analysis of structural oppression and power in HCI and design. ACM Transactions on Computer-Human Interaction.

Etikan, I., Musa, S.A. and Alkassim, R.S. 2016. Comparison of Convenience Sampling. American Journal of Theoretical and Applied Statistics. (2016). DOI:https://doi.org/10.11648/j.ajtas.20160501.11.

Faulkner, S.L. and Lannutti, P.J. 2016. Representations of lesbian and bisexual women’s sexual and relational health in online video and textbased sources. Computers in Human Behavior. (2016). DOI:https://doi.org/10.1016/j.chb.2016.06.039.

Fisher CB, Fried AL, Desmond M, Macapagal K, Mustanski B. Facilitators and Barriers to Participation in PrEP HIV Prevention Trials Involving Transgender Male and Female Adolescents and Emerging Adults. AIDS Educ Prev. 2017;29(3):205-217.

Fisher, K.E., Bishop, A.P., Magassa, L. and Fawcett, P. 2014. Action! Co-designing interactive technology with immigrant teens. ACM International Conference Proceeding Series (2014).

Fisher, K.E., Yefimova, K. and Yafi, E. 2016. “Future’s butterflies:” Co-designing ICT wayfaring technology with refugee Syrian youth. Proceedings of IDC 2016 - The 15th International Conference on Interaction Design and Children (2016).

Foucault, M. (1990). The history of sexuality: An introduction, volume I. Trans. Robert Hurley. New York: Vintage, 95.

Foucault, M., Davidson, A. I., & Burchell, G. (2008). The birth of biopolitics: lectures at the Collège de France, 1978-1979. Springer.

Fox, J. and Ralston, R. 2016. Queer identity online: Informal learning and teaching experiences of LGBTQ individuals on social media. Computers in Human Behavior. (2016). DOI:https://doi.org/10.1016/j.chb.2016.06.009.

Freudenberg N, Rogers MA, Ritas C, Nerney M. Policy analysis and advocacy: an approach to community based participatory research. In: Israel BA, Eng E, Schulz AJ, Parker EA, eds. Methods in Community-Based Participatory Research for Health. San Francisco, CA: JosseyBass; 2005:349–370.

Fried, C. Privacy. The Yale Law Journal, Vol. 77, No.3. (Jan., 1968), pp. 475-493.

Fried, C. (2013). An anatomy of values. In An Anatomy of Values. Harvard University Press.

G. Bauer, A. Devor, M. Heinz, Z. Marshall, A. Pullen Sansfaçon, and J. Pyne. 2019. CPATH Ethical Guidelines for Research Involving Transgender People & Communities. Retrieved from https://cpath.ca/wp-content/uploads/2019/ 08/CPATH-Ethical-Guidelines-EN.pdf.

G. Leonard and L. Misumi. 2016. W.A.I.T. (Why Am I Talking?): A dialogue on solidarity, allyship, and supporting the struggle for racial justice without reproducing white supremacy. Harvard Journal of African American Public Policy 61–74.

G. M. Russell and J. S. Bohan. 2016. Institutional allyship for LGBT equality: Underlying processes and potentials for change. Journal of Social Issues 72, 2 (2016), 335–354. DOI:https://doi.org/10.1111/josi.12169

G. M. Russell. 2011. Motives of heterosexual allies in collective action for equality. Journal of Social Issues 67, 2 (2011), 376–393. DOI:https://doi.org/10.1111/j.1540-4560.2011.01703.x

G. R. Hayes. 2011. The relationship of action research to human-computer interaction. ACM Transactions on Computer-Human Interaction 18, 3 (2011) Article 15, 20 pages. DOI:https://doi.org/10.1145/1993060.1993065

G. R. Williamson and S. Prosser. 2002. Action research: Politics, ethics and participation. Journal of Advanced Nursing 40, 5 (2002), 587–593. DOI:https://doi.org/10.1046/j.1365-2648.2002.02416.x.

Gamble VN. The Tuskegee Syphilis Study and women's health. J Am Med Womens Assoc. 1997;52(4):195–196.

Garofalo R, Deleon J, Osmer E, Doll M, Harper GW. Overlooked, misunderstood and at-risk: exploring the lives and HIV risk of ethnic minority male-to-female transgender youth. J Adolesc Health. 2006;38(3):230-236.

Gault, M. (2022, December 12). Facial recognition researcher left a trans database exposed for years after using images without permission. VICE. https://www.vice.com/en/article/93aj3z/facial-recognition-researcher-left-a-trans-database-exposed-for-years-after-using-images-without-permission

Geeng, C. (2022). Analyzing Usable Security, Privacy, and Safety Through Identity-Based Power Relations (Doctoral dissertation, University of Washington).

Geeng, C., Harris, M., Redmiles, E., & Roesner, F. (2022). " Like Lesbians Walking the Perimeter": Experiences of {US}.{LGBTQ+} Folks With Online Security, Safety, and Privacy Advice. In 31st USENIX Security Symposium (USENIX Security 22) (pp. 305-322).

Geeng, C., Hutson, J., & Roesner, F. (2020, August). Usable sexurity: Studying people's concerns and strategies when sexting. In Proceedings of the Sixteenth USENIX Conference on Usable Privacy and Security (pp. 127-144).

Ghosh, A. K., Badillo-Urquiola, K., Guha, S., LaViola Jr, J. J., & Wisniewski, P. J. (2018, April). Safety vs. surveillance: what children have to say about mobile apps for parental control. In Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems (pp. 1-14).

Ghoshal, S., & Bruckman, A. (2019). The role of social computing technologies in grassroots movement building. ACM Transactions on Computer-Human Interaction (TOCHI), 26(3), 1-36.

Goldfarb, E. S., & Lieberman, L. D. (2021). Three decades of research: The case for comprehensive sex education. Journal of Adolescent Health, 68(1), 13-27.

Grant J, Mottet L, Tanis J, Harrison J, Herman J, Keisling M. Injustice at Every Turn: A Report of the National Transgender Discrimination Survey. Washington: National Center for Transgender Equality and National Gay and Lesbian Task Force;2011.

Gray, M. L. (2009). Out in the Country. New York University Press.

Green, M. (2021). Resistance as participation: Queer theory's applications for HIV health technology design. Technical Communication Quarterly, 30(4), 331-344.

Gridley, S.J., Crouch, J.M., Evans, Y., Eng, W., Antoon, E., Lyapustina, M., Schimmel-Bristow, A., Woodward, J., Dundon, K., Schaff, R.N., McCarty, C., Ahrens, K. and Breland, D.J. 2016. Youth and Caregiver Perspectives on Barriers to GenderAffirming Health Care for

Transgender Youth. Journal of Adolescent Health. (2016). DOI:https://doi.org/10.1016/j.jadohealth.2016.03.017.

Grimes, A., Bednar, M., Bolter, J. D., & Grinter, R. E. (2008, November). EatWell: sharing nutrition-related memories in a low-income community. In Proceedings of the 2008 ACM conference on Computer supported cooperative work (pp. 87-96).

Griner SB, Vamos CA, Thompson EL, Logan R, Vazquez-Otero C, Daley EM. The Intersection of Gender Identity and Violence: Victimization Experienced by Transgender College Students. J Interpers Violence. 2020;35(23-24):5704-5725.

Griner, S.B., Vamos, C.A., Thompson, E.L., Logan, R., Vázquez-Otero, C. and Daley, E.M. 2017. The Intersection of Gender Identity and Violence: Victimization Experienced by Transgender College Students. Journal of Interpersonal Violence.

Guha, M.L., Druin, A., Chipman, G., Fails, J.A., Simms, S. and Farber, A. 2004. Mixing ideas: A new technique for working with young children as design partners. Proceedings of the 2004 Conference on Interaction Design and Children: Building a Community, IDC 2004 (2004).

Guyan, K. (2022). Queer data: Using gender, sex and sexuality data for action. Bloomsbury Publishing.

H. Castleden, T. Garvin, and H. First Nation. 2008. Modifying photovoice for community-based participatory indigenous research. Social Science and Medicine 66, 6 (2008), 1393–1405. DOI:https://doi.org/10.1016/j.socscimed.2007.11. 030

H. W. J. Rittel and M. M. Webber. 1973. Dilemmas in a general theory of planning. Policy Sciences. 4, 2 (1973), 155–169. DOI:https://doi.org/10.1007/BF01405730

Haimson, O. L., Dame-Griff, A., Capello, E., & Richter, Z. (2021). Tumblr was a trans technology: the meaning, importance, history, and future of trans technologies. Feminist media studies, 21(3), 345-361.

Haimson, O. L., Delmonaco, D., Nie, P., & Wegner, A. (2021). Disproportionate removals and differing content moderation experiences for conservative, transgender, and black social media users: Marginalization and moderation gray areas. Proceedings of the ACM on Human-Computer Interaction, 5(CSCW2), 1-35.

Haimson, O. L., Gorrell, D., Starks, D. L., & Weinger, Z. (2020, April). Designing trans technology: Defining challenges and envisioning community-centered solutions. In Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems (pp. 1-13).

Haimson, O. L., Nham, K., Thach, H., & DeGuia, A. (2023). How Transgender People and Communities Were Involved in Trans Technology Design Processes.

Halberstam, J. (2011). The queer art of failure. In The queer art of failure. Duke University Press.

Haley, S.G., Tordoff, D.M., Kantor, A.Z., Crouch, J.M. and Ahrens, K.R. 2019. Sex Education for Transgender and Non-Binary Youth: Previous Experiences and Recommended Content. Journal of Sexual Medicine. (2019). DOI:https://doi.org/10.1016/j.jsxm.2019.08.009.

Hardy, J. and Vargas, S. 2019. Participatory design and the future of rural LGBTQ communities. DIS 2019 Companion - Companion Publication of the 2019 ACM Designing Interactive Systems Conference (2019).

Harrington, C., Erete, S., & Piper, A. M. (2019). Deconstructing community-based collaborative design: Towards more equitable participatory design engagements. Proceedings of the ACM on Human-Computer Interaction, 3(CSCW), 1-25.

Hayes, G. R. (2011). The relationship of action research to human-computer interaction. ACM Transactions on Computer-Human Interaction (TOCHI), 18(3), 1-20.

Healthwrights (1998). Nothing About Us Without Us: Developing Innovative Technologies For, By and With Disabled Persons. Palo Alto CA. ISBN 9780965558532.

Healthy People 2010: Companion Document for Lesbian, Gay, Bisexual, and Transgender (LGBT) Health. San Francisco, CA: Gay and Lesbian Medical Association; 2001. Available at: http://www.glma.org/_data/ n_0001/resources/live/HealthyCompanionDoc3.pdf. Accessed September 14, 2007.

Healthy People 2030, U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion. From https://health.gov/healthypeople/objectives-and-data/social-determinants-health

Hillier-Brown FC, Bambra CL, Cairns J-M, et al. A systematic review ofthe effectiveness of individual, community and societal level interventionsat reducing socioeconomic inequalities in obesity amongst children.BMC Public Health. 2014;14:1483–1490.

Hirsch, T. (2020, April). Practicing without a license: Design research as psychotherapy. In Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems (pp. 1-11).

Hong, M.K., Wilcox, L., Machado, D., Olson, T.A. and Simoneaux, S.F. 2016. Care partnerships: Toward technology to support teens' participation in their health care. Conference on Human Factors in Computing Systems - Proceedings (2016).

Hsiu-Fang Hsieh and Sarah E. Shannon, 2005. "Three approaches to qualitative content analysis," Qualitative Health Research, volume 15, number 9, pp. 1,277–1,288.

I. Dey. 1999. Grounding Grounded Theory: Guidelines for Qualitative Inquiry. Emerald Publishing Limited.

I. F. Ogbonnaya-Ogburu, A. D. Smith, A. To, and K. Toyama. 2020. Critical race theory for HCI. In Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems. 1–16. DOI: https://doi.org/10.1145/3313831.3376392

Indigenous Action. 2014. Accomplices Not Allies: Abolishing the Ally Industrial Complex. Retrieved from http://www.indigenousaction.org/accomplices-not-allies-abolishing-the-ally-industrial-complex/.

Irani, L. (2018). "Design thinking": Defending Silicon Valley at the apex of global labor hierarchies. Catalyst: Feminism, Theory, Technoscience, 4(1), 1-19.

Israel BA, Schulz AJ, Parker EA, et al.Community-based participatory research: policy recommendations for promoting a partnership approach in health research. Educ Health 2001;14: 182–197.

Israel, B. A., Coombe, C. M., Cheezum, R. R., Schulz, A. J., McGranaghan, R. J., Lichtenstein, R., ... & Burris, A. (2010). Community-based participatory research: a capacity-building approach for policy advocacy aimed at eliminating health disparities. American journal of public health, 100(11), 2094-2102.

Israel, B. A., Schulz, A. J., Parker, E. A., Becker, A. B., Allen, A. J., Guzman, J. R., & Lichtenstein, R. (2017). Critical issues in developing and following CBPR principles. Community-based participatory research for health: Advancing social and health equity, 3, 32-35.

J. Hui, N. R. Barber, W. Casey, S. Cleage, D. C. Dolley, F. Worthy, K. Toyama, and T. R. Dillahunt. 2020. Community collectives: Low-tech social support for digitally-engaged entrepreneurship. In Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems. 1–15. DOI:https://doi.org/10.1145/3313831.3376363

J. K. Walter, J. F. Burke, and M. M. Davis. 2013. Research participation by low-income and racial/ethnic minority groups: How payment may change the balance. Clinical and Translational Science 6, 5 (2013), 363–371. DOI:https:// doi.org/10.1111/cts.12084

J. Kluttz, J. Walker, and P. Walter. 2019. Unsettling allyship, unlearning and learning towards decolonising solidarity. Studies in the Education of Adults 52, 1 (2019), 49–66. DOI:https://doi.org/10.1080/02660830.2019.1654591

J. L. Laws. 1975. The psychology of tokenism: An analysis. Sex Roles 1, 51–67 (1975). DOI: https://doi.org/10.1007/ BF00287213

J. O. Thomas, N. Joseph, A. Williams, C. Crum, and J. Burge. 2018. Speaking truth to power: Exploring the intersectional experiences of Black women in computing. In Proceedings of the 2018 Research on Equity and Sustained Participation in Engineering, Computing, and Technology (RESPECT'18). DOI: https://doi.org/10.1109/RESPECT.2018. 8491718

J. P. Dimond, M. Dye, D. Larose, and A. S. Bruckman. 2013. Hollaback!: The role of collective storytelling online in a social movement organization. In Proceedi ngs of the ACM Conference on Computer Supported Cooperative Work (CSCW'13). 477–490. DOI:https://doi.org/10.1145/2441776.2441831

J. Powell and A. Kelly. 2018. Accomplices in the academy in the age of Black Lives Matter. Journal of Critical Thought and Praxis 6, 2 (2018). DOI:https://doi.org/10.31274/jctp-180810-73

J. T. O'Leary, S. Zewde, J. Mankoff, and D. K. Rosner. 2019. Who gets to future? Race, representation, and design methods in Africatown. In Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems. Paper 561, 1–13. DOI: https://doi.org/10.1145/3290605.3300791

J. Vines, R. McNaney, R. Clarke, S. Lindsay, J. McCarthy, S. Howard, M. Romero, and J. Wallace. 2013. Designing for- and with- vulnerable people. In Proceedings of the CHI'13 Extended Abstracts on Human Factors in Computing Systems. 3231–3234. DOI:https://doi.org/10.1145/2468356.2479654

J. Vines, R. McNaney, S. Lindsay, J. Wallace, and J. McCarthy. 2014. Designing for and with vulnerable people. Interactions 21, 1 (2014), 44–46. DOI:https://doi.org/10.1145/2543490

J. Waycott, G. Wadley, S. Schutt, A. Stabolidis, and R. Lederman. 2015. The challenge of technology research in sensitive settings: Case studies in "Sensitive HCI." In Proceedings of the Annual Meeting of the Australian Special Interest Group for Computer Human Interaction (OzCHI'15). 240–249. DOI: https://doi.org/10.1145/2838739.2838773

Jackson, S.J., Gillespie, T. and Payette, S. 2014. The policy knot: Re-integrating policy, practice and design in CSCW studies of social computing. Proceedings of the ACM Conference on Computer Supported Cooperative Work, CSCW (2014).

Jonathan Kemp. 2009. Queer past, queer present, queer future. Graduate Journal of Social Science 6, 1 (2009), 3–23

Joseph, C. (2019, November 8). Instagram's murky 'shadow bans' just serve to censor marginalised communities | Chanté Joseph. The Guardian. Retrieved April 5, 2022, from https://www.theguardian.com/commentisfree/2019/nov/08/instagram-shadow-bans-marginalised-communities-queer-plus-sized-bodies-sexually-suggestive

K. A. Siek, J. S. LaMarche, and J. Maitland. 2009. Bridging the information gap: Collaborative technology design with low-income at-risk families to engender healthy behaviors. In Proceedings of the 21st Annual Conference of the Australian Computer-Human Interaction Special Interest Group - Design: Open 24/7 (OZCHI'09). 89–96. DOI:https: //doi.org/10.1145/1738826.1738841

K. Caldwell. 2010. We exist: Intersectional in/visibility in bisexuality & disability. Disability Studies Quarterly 30, 3/4 (2010). DOI:https://doi.org/10.18061/dsq.v30i3/4.1273

K. Crenshaw. 1991. Mapping the margins: Intersectionality, identity politics, and violence against women of color. Stanford Law Review 43, 6 (1991), 1241–1299. DOI:https://doi.org/10.2307/1229039

K. Heimerl, S. Hasan, K. Ali, E. Brewer, and T. Parikh. 2013. Local, sustainable, small-scale cellular networks. In Proceedings of the 6th International Conference on Information and Communication Technologies and Development: Full Papers: Volume 1 (ICTD'13). Association for Computing Machinery, New York, NY, 2–12. DOI:https://doi.org/10.1145/2516604.2516616

K. M. Unertl, C. L. Schaefbauer, T. R. Campbell, C. Senteio, K. A. Siek, S. Bakken, and T. C. Veinot. 2016. Integrating community-based participatory research and informatics approaches to improve the engagement and health of underserved populations. Journal of the American Medical Informatics Association 23, 1 (2016), 60–73. DOI:https://doi.org/10.1093/jamia/ocv094

K. Moon and D. Blackman. 2014. A guide to understanding social science research for natural scientists. Conservation Biology 28, 5 (2014), 1167–1177. DOI: https://doi.org/10.1111/cobi.12326

K. P. Morgan. 1996. Describing the emperor's new clothes: Three myths of educational (In-)equity. In The Gender Question in Education. A. Diller, B. Houston, K. P. Morgan, M. Ayim, and K. P. Morgan (Eds.), Routledge.

K. Spiel, A. M. Walker, M. A. DeVito, J. Birnholtz, P. Barlas, A. Ahmed, J. R. Brubaker, O. Keyes, E. Brulé, A. Light, J. Hardy, J. A. Rode, and G. Kannabiran. 2019. Queer(ing) HCI: Moving forward in theory and practice. In Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems. Paper SIG11, 1–4. DOI:https://doi.org/10.1145/3290607.3311750

K. V. L. England. 1994. Getting personal: Reflexivity, positionality, and feminist research. Professional Geographer 46, 1 (1994), 80–89. DOI:https://doi.org/10.1111/j.0033-0124.1994.00080.x

Kahn, N. F., Anan, Y. H., Bocek, K. M., Christakis, D. A., Richardson, L. P., Pratt, W., & Sequeira, G. M. (2023). Understanding Transgender and Gender-Diverse Youth's Experiences Receiving Care via Telemedicine: Qualitative Interview Study. JMIR Pediatrics and Parenting, 6, e42378.

Katz, Ralph V.; Green, B. Lee; Kressin, Nancy R.; Kegeles, S. Stephen; Wang, Min Qi; James, Sherman A.; Russell, Stefanie L.; Claudio, Cristina; McCallum, Jan M. (November 1, 2008). "The legacy of the Tuskegee Syphilis Study: assessing its impact on willingness to participate in biomedical studies". Journal of Health Care for the Poor and Underserved.

19 (4): 1168–1180. doi:10.1353/hpu.0.0067. ISSN 1049-2089. PMC 2702151. PMID 19029744.

Keyes, O. (2018). The misgendering machines: Trans/HCI implications of automatic gender recognition. Proceedings of the ACM on human-computer interaction, 2(CSCW), 1-22.

Keyes, O., & Austin, J. (2022). Feeling fixes: Mess and emotion in algorithmic audits. Big Data & Society, 9(2), 20539517221113772.

Koster, R., Baccar, K. and Lemelin, R.H. 2012. Moving from research ON, to research with and for Indigenous communities: A critical reflection on community-based participatory research. Canadian Geographer. (2012). DOI:https://doi.org/10.1111/j.1541-0064.2012.00428.x.

Kumar and S. Bardzell. 2020. An unofficial guide to seven stages of reviewing for CHI. Retrieved from https:// nehakumar.medium.com/an-unofficial-guide-to-seven-stages-of-reviewing-for-chi-7938880fc895

Kussin-Shoptaw AL, Fletcher JB, Reback CJ. Physical and/or Sexual Abuse Is Associated with Increased Psychological and Emotional Distress Among Transgender Women. LGBT Health. 2017;4(4):268-274.

L. Dombrowski, E. Harmon, and S. Fox. 2016. Social justice-oriented interaction design: Outlining key design strategies and commitments. In Proceedings of the 2016 ACM Conference on Designing Interactive Systems: Fuse (DIS'16). 656–671. DOI:https://doi.org/10.1145/2901790.2901861

L. Duggan. 2002. The new homonormativity: The sexual politics of neoliberalism. In Materializing Democracy Toward a Revitalized Cultural Politics. R. Castronovo and D. Nelson (Eds.), Duke University Press.

L. Irani, J. Vertesi, P. Dourish, K. Philip, and R. E. Grinter. 2010. Postcolonial computing: A lens on design and development. In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems. 1311–1320. DOI:https: //doi.org./10.1145/1753326.1753522

L. Malinverni and N. Pares. 2017. An autoethnographic approach to guide situated ethical decisions in participatory design with teenagers. Interacting with Computers. (2017). DOI: https://doi.org/10.1093/iwc/iww031

L. Mizock and K. V. Page. 2016. Evaluating the ally role: Contributions, limitations, and the activist position in counseling and psychology. Journal for Social Action in Counseling and Psychology 8, 1 (2016). DOI:https://doi.org/ 10.33043/JSACP.8.1.17-33

L. Palen. 2014. Empirical Epistemologies Applied to Human-Centered Computing Research: 2014. Retrieved from https://cmci.colorado.edu/~palen/EmpiricalEpistemologiesforHCC-7.pdf.

L. S. Rodopoulos. 2004. Becoming an ally: Breaking the cycle of oppression (2nd edn). Australian Social Work 57, 4 (2004), 410–412. DOI:https://doi.org/10.1111/j.0312-407x.2004.00170.x

L. T. Smith. 2012. Decolonizing Methodologies: Research and Indigenous Peoples (2nd ed.). Zed Books.

L. Thompson and S. Reinharz. 1992. Feminist methods in social research. Journal of Marriage and the Family 54, 4 (1992), 996–997. DOI:https://doi.org/10.2307/353180

L. Winner. 1985. Do artifacts have politics? Daedalus 109, 1 (1985), 26–38 DOI: https://doi.org/10.4324/ 9781315259697-21

LeMaster, B. (2017). Notes on trans relationality. QED: A Journal in GLBTQ Worldmaking, 4(2), 84-92.

Lett, E., Adekunle, D., McMurray, P., Asabor, E. N., Irie, W., Simon, M. A., ... & McLemore, M. R. (2022). Health Equity Tourism: Ravaging the Justice Landscape. Journal of medical systems, 46(3), 1-6.

Liang, C., Hutson, J. A., & Keyes, O. (2020). Surveillance, stigma & sociotechnical design for HIV. First Monday, 25(10). https://doi.org/10.5210/fm.v25i10.10274

Liang, C., Hutson, J., & Keyes, O. (2020). Surveillance, stigma & sociotechnical design for HIV. arXiv preprint arXiv:2006.04882.

Light, A. (2011). HCI as heterodoxy: Technologies of identity and the queering of interaction with computers. Interacting with computers, 23(5), 430-438.

M. Cifor, P. Garcia, T. L. Cowan, J. Rault, T. Sutherland, A. Chan, J. Rode, A. L. Hoffmann, N. Salehi, and L. Nakamura. 2019. Feminist Data Manifest-No. Retrieved from https://www.manifestno.com/.

M. Dye, D. Nemer, L. R. Pina, N. Sambasivan, A. S. Bruckman, and N. Kumar. 2017. Locating the internet in the parks of Havana. In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems. 3867–3878. DOI:https: //doi.org/10.1145/3025453.3025728

M. Fine. 1994. Working the hyphens: Reinventing self and other in qualitative research. In Handbook of Qualitative Research. SAGE. Retrieved from http://www.uky.edu/~addesa01/documents/Fine_Hyphens.pdf

M. Franks. 2002. Feminisms and cross-ideological feminist social research: Standpoint, situatedness and positionality—Developing cross-ideological feminist research. Journal of International Women’s Studies 3, 2 (2002), 38–50. Retrieved from http://vc.bridgew.edu/jiws/vol3/iss2/3.

M. Fricker. 2007. Epistemic Injustice: Power and the Ethics of Knowing. Oxford University Press.

M. Gallagher. 2008. “Power is not an evil”: Rethinking power in participatory methods. Children’s Geographies 6, 2 (2008), 137–150. DOI:https://doi.org/10.1080/14733280801963045

M. J. Muller. 2003. Participatory design: The third space in HCI. In Human-Computer Interaction Handbook (2nd ed.). CRC Press. DOI:https://doi.org/10.1145/153571.255960

M. K. Scheuerman, K. Spiel, O. Haimson, F. Hamidi, and S. M. Branham. 2019. HCI Guidelines for Gender Equity and Inclusivity. Retrieved from https://www.morgan-klaus.com/sigchi-gender-guidelines.

M. K. Scheuerman, S. M. Branham, and F. Hamidi. 2018. Safe spaces and safe places: Unpacking technology-mediated experiences of safety and harm with transgender people. Proceedings of the ACM on Human-Computer Interaction 2, CSCW (2018) Article 155. DOI:https://doi.org/10.1145/3274424

M. Lugones. 2007. Heterosexualism and the colonial/modern gender system. Hypatia. 22, 1 (2007), 186–219. DOI: https://doi.org/10.1111/j.1527-2001.2007.tb01156.x

M. Minkler. 2004. Ethical challenges for the “outside” researcher in community-based participatory research. Health Education and Behavior 31, 6 (2004), 684–697. DOI:https://doi.org/10.1177/1090198104269566

M. Tanis and T. Postmes. 2005. Short communication a social identity approach to trust: Interpersonal perception, group membership and trusting behaviour. European Journal of Social Psychology (2005). DOI: https://doi.org/10. 1002/ejsp.256

M. Wong-Villacres, A. Kumar, A. Vishwanath, N. Karusala, B. DiSalvo, and N. Kumar. 2018. Designing for intersections. In Proceedings of the 2018 Designing Interactive Systems Conference (DIS’18). 45–58. DOI:https://doi.org/10. 1145/3196709.3196794

MacLeod, H., Jelen, B., Prabhakar, A., Oehlberg, L., Siek, K. and Connelly, K. 2016. Asynchronous Remote Communities (ARC) for researching distributed populations. PervasiveHealth: Pervasive Computing Technologies for Healthcare (2016).

MacLeod, H., Jelen, B., Prabhakar, A., Oehlberg, L., Siek, K., & Connelly, K. (2017). A guide to using asynchronous remote communities (ARC) for researching distributed populations. EAI Endorsed Transactions on Pervasive Health and Technology, 3(11).

Maestre, J. F., Zdziarska, P., Min, A., Baglione, A. N., Chung, C. F., & Shih, P. C. (2021). Not another medication adherence app: Critical reflections on addressing public HIV-related stigma through design. Proceedings of the ACM on Human-Computer Interaction, 4(CSCW3), 1-28.

Maestre, J.F., MacLeod, H., Connelly, C.L., Dunbar, J.C., Beck, J., Siek, K.A. and Shih, P.C. 2018. Defining through expansion: Conducting asynchronous remote communities (ARC) Research with stigmatized groups. Conference on Human Factors in Computing Systems - Proceedings (2018).

Manifesto to Align HIV Prevention Research with Trans and Gender-Diverse Realities. New York City: AVAC

Marcu, G., Dowshen, N., Saha, S., Sarreal, R.R. and Andalibi, N. 2016. TreatYoSelf: Empathy-driven behavioral intervention for marginalized youth living with HIV. PervasiveHealth: Pervasive Computing Technologies for Healthcare (2016).

Matthew Cox. 2018. Shifting Grounds as the New Status Quo: Examining Queer

Mayer, K. H., Bradford, J. B., Makadon, H. J., Stall, R., Goldhammer, H., & Landers, S. (2008). Sexual and gender minority health: what we know and what needs to be done. American journal of public health, 98(6), 989-995.

McCann E, Brown M. Vulnerability and Psychosocial Risk Factors Regarding People who Identify as Transgender. A Systematic Review of the Research Evidence. Issues Ment Health Nurs. 2018;39(1):3-15.

McCartney, G., Popham, F., McMaster, R., & Cumbers, A. (2019). Defining health and health inequalities. Public health, 172, 22-30.

Meadows, D. H. (2008). Thinking in systems: A primer. chelsea green publishing

Metatla, O. and Cullen, C. 2018. "Bursting the assistance bubble": Designing inclusive technology with children with mixed visual abilities. Conference on Human Factors in Computing Systems - Proceedings (2018).

Michelson, R., DeWitt, A., Nagar, R., Hiniker, A., Yip, J., Munson, S. A., & Kientz, J. A. (2021). Parenting in a pandemic: juggling multiple roles and managing technology use in family life during COVID-19 in the United States. Proceedings of the ACM on Human-Computer Interaction, 5(CSCW2), 1-39.

Minalga, B., Chung, C., Davids, J. D., Martin, A., Perry, N. L., & Shook, A. (2022). Research on transgender people must benefit transgender people. The Lancet, 399(10325), 628.

Minkler M, Vasquez VB, Chang C, et al. Promoting Healthy Public Policy Through Community-Based Participatory Research: Ten Case Studies. Berkeley, CA: University of California Berkeley and PolicyLink; 2008.

Minkler M, Wallerstein N, eds. Community-Based Participatory Research for Health: From Process to Outcomes. 2nd ed. San Francisco, CA: Jossey Bass; 2008.

Minkler M. Ethical challenges for the "outside" researcher in community-based participatory research. Health Educ Behav. 2004;31(6):684–697.

Mitchell, K.J., Ybarra, M.L., Korchmaros, J.D. and Kosciw, J.G. 2014. Accessing sexual health information online: Use, motivations and consequences for youth with different sexual orientations. Health Education Research. (2014). DOI:https://doi.org/10.1093/her/cyt071.

Moeggenberg, Z. C., & Walton, R. (2019, October). How queer theory can inform design thinking pedagogy. In Proceedings of the 37th ACM International Conference on the Design of Communication (pp. 1-9).

Movement Advancement Project. April 2021. LGBTQ Policy Spotlight: Efforts to Ban Health Care for Transgender Youth. www.lgbtmap.org/2021-spotlight-health-care-bans.

N. B. Wallerstein and B. Duran. 2006. Using community-based participatory research to address health disparities. Health Promotion Practice. (2006). DOI: https://doi.org/10.1177/1524839906289376

N. Berenstain. 2016. Epistemic exploitation.Ergo, an Open Access Journal of Philosophy 3, 22 (2016). DOI:https://doi. org/10.3998/ergo.12405314.0003.022

N. Dell and N. Kumar. 2016. The ins and outs of HCI for development. In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems. 2220–2232. DOI:https://doi.org/10.1145/2858036.2858081

N. J. Evans and V. A. Wall. 1991. Beyond Tolerance: Gays, Lesbians and Bisexuals on Campus. UPA.

N. J. Evans, J. L. Assadi, and T. K. Herriott. 2005. Encouraging the development of disability allies. New Directions for Student Services 2005, 110 (2005), 67–79. DOI:https://doi.org/10.1002/ss.166

N. Shaprio. 2020. Viral #medbikini response to controversial manuscript leads editor to retract article. Forbes. Retrieved from https://www.forbes.com/sites/ninashapiro/2020/07/25/viral-medbikini-response-to-controversialmanuscript-leads-editor-to-retract-article/?sh=283a146c1f47.

Noronha, N. (2019, October). This is how queer Indian artists are responding to Instagram's crackdown on nudity. VICE. Retrieved April 5, 2022, from https://www.vice.com/en/article/43k87d/this-is-how-queer-indian-artists-are-responding-to-instagrams-crackdown-on-nudity

O. Keyes, B. Peil, R. M. Williams, and K. Spiel. 2020. Reimagining (Women's) health: HCI, gender and essentialised embodiment. ACM Transactions on Computer-Human Interaction 27, 4 (2020) Article 25, 42 pages. DOI:https://doi. org/10.1145/3404218

O. Keyes, J. Hoy, and M. Drouhard. 2019. Human-computer insurrection: Notes on an Anarchist HCI. In Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems. Paper 339, 1–13. DOI:https://doi.org/10.1145/ 3290605.3300569

O. Keyes. 2018. The misgendering machines: Trans/HCI implications of automatic gender recognition. Proceedings of the ACM on Human-Computer Interaction 2, CSCW (2018), Article 88, 22 pages. DOI:https://doi.org/10.1145/3274357

Ogbonnaya-Ogburu, I. F., Smith, A. D., To, A., & Toyama, K. (2020, April). Critical race theory for HCI. In Proceedings of the 2020 CHI conference on human factors in computing systems (pp. 1-16).

Olson-Kennedy, J., Cohen-Kettenis, P. T., Kreukels, B. P., Meyer-Bahlburg, H. F., Garofalo, R., Meyer, W., & Rosenthal, S.M. 2016. Research priorities for gender nonconforming/transgender youth: gender identity development and biopsychosocial outcomes. Current opinion in endocrinology, diabetes, and obesity. 23, 2 (2016), 172.

Oudshoorn, N. (2020). Resilient cyborgs: Living and dying with pacemakers and defibrillators. Springer Nature.

Ovalle, A., Subramonian, A., Gautam, V., Gee, G., & Chang, K. W. (2023). Factoring the Matrix of Domination: A Critical Review and Reimagination of Intersectionality in AI Fairness. arXiv preprint arXiv:2303.17555.

P. A. L. Cochran, C. A. Marshall, C. Garcia-Downing, E. Kendall, D. Cook, L. McCubbin, and R. M. S. Gover. 2008. Indigenous ways of knowing: Implications for participatory research and community. American Journal of Public Health 98, 1 (2008), 22–27. DOI:https://doi.org/10.2105/AJPH.2006.093641

P. E. Hopkins. 2009. Women, men, positionalities and emotion: Doing feminist geographies of religion. ACME: An International Journal for Critical Geographies 8, 1 (2009), 1–17. Retrieved from https://acme-journal.org/index.php/ acme/article/view/818.

P. H. Collins. 2002. Black Feminist Thought: Knowledge, Consciousness, and the Politics Of Empowerment. Routledge. DOI:https://doi.org/10.2307/2074808

P. Harris. 1995. Who am I? Concepts of disability and their implications for people with learning difficulties. Disability & Society 10, 3 (1995), 341–352. DOI:https://doi.org/10.1080/09687599550023570

P. Hill Collins and S. Bilge. 2016. What is intersectionality? Using intersectionality as an analytic tool. Intersectionality 61, 11 (2016), 1036–1039. DOI:https://doi.org/10.1016/j.scriptamat.2009.08.024

P. I. Fusch and L. R. Ness. 2015. Are we there yet? Data saturation in qualitative research. Qualitative Report 20, 9 (2015), 1408–1416. Retrieved from https://nsuworks.nova.edu/tqr/vol20/iss9/3.

P. Moss, J. P. Jones, H. J. Nast, and S. M. Roberts. 1999. Thresholds in feminist geography: Difference, methodology, representation. Economic Geography 27, 11 (1999), 1659–1662. DOI:https://doi.org/10.2307/144254

Parker, A., Kantroo, V., Lee, H. R., Osornio, M., Sharma, M., & Grinter, R. (2012, May). Health promotion as activism: building community capacity to effect social change. In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (pp. 99-108).

Pierce, J., Fox, S., Merrill, N., & Wong, R. (2018). Differential vulnerabilities and a diversity of tactics: What toolkits teach us about cybersecurity. Proceedings of the ACM on Human-Computer Interaction, 2(CSCW), 1-24.

Pihkala, S., & Karasti, H. (2018, August). Politics of mattering in the practices of participatory design. In Proceedings of the 15th Participatory Design Conference: Short Papers, Situated Actions, Workshops and Tutorial-Volume 2 (pp. 1-5).

Pitt, C. and Davis, K. 2017. Designing together?: Group dynamics in participatory digital badge design with teens. IDC 2017 - Proceedings of the 2017 ACM Conference on Interaction Design and Children (2017).

Poole, E.S. and Peyton, T. 2013. Interaction design research with adolescents: Methodological challenges and best practices. ACM International Conference Proceeding Series (2013).

Prabhakar, A. S., Guerra-Reyes, L., Kleinschmidt, V. M., Jelen, B., MacLeod, H., Connelly, K., & Siek, K. A. (2017, May). Investigating the suitability of the asynchronous, remote, community-based method for pregnant and new mothers. In Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems (pp. 4924-4934).

Pyrrho, M., Cambraia, L., & de Vasconcelos, V. F. (2022). Privacy and Health Practices in the Digital Age. The American Journal of Bioethics, 1-10.

R. Benjamin. 2020. Race after technology: Abolitionist tools for the new jim code. Social Forces 98, 4 (2020), 1–3. DOI:https://doi.org/10.1093/sf/soz162

R. Charlotte Smith, H. Winschiers-Theophilus, A. Paula Kambunga, and S. Krishnamurthy. 2020. Decolonizing participatory design: Memory making in Namibia. In Proceedings of the 16th Participatory Design Conference 2020. 96– 106. DOI:https://doi.org/10.1145/3385010.3385021

R. Cornejo, R. Brewer, C. Edasis, and A. M. Piper. 2016. Vulnerability, sharing, and privacy: Analyzing art therapy for older adults with dementia. In Proceedings of the ACM Conference on Computer Supported Cooperative Work (CSCW'16). 1572–1583. DOI:https://doi.org/10.1145/2818048.2819960

R. Dutt-Ballerstadt. 2020. In Our Own Words: Institutional betrayals. Retrieved from https://www.insidehighered. com/advice/2020/03/06/underrepresented-faculty-members-share-real-reasons-they-have-left-various.

R. Gay. 2016. On making Black Lives Matter: 2016. Retrieved from https://www.marieclaire.com/culture/a21423/ roxane-gay-philando-castile-alton-sterling/.

R. Heeks. 2002. Information systems and developing countries: Failure, success, and local improvisations. Information Society 18, 2 (2002), 101–112. DOI:https://doi.org/10.1080/01972240290075039

R. Imrie. 2012. Universalism, universal design and equitable access to the built environment. Disability and Rehabilitation 34, 10 (2012), 873–882. DOI:https://doi.org/10.3109/09638288.2011.624250

R. Koster, K. Baccar, and R. H. Lemelin. 2012. Moving from research ON, to research with and for indigenous communities: A critical reflection on community-based participatory research. Canadian Geographer 56, 2 (2012). DOI: https://doi.org/10.1111/j.1541-0064.2012.00428.x

R. N. Brewer. 2017. Understanding and Developing Interactive Voice Response Systems to Support Online Engagement of Older Adults. Ph.D. Dissertation. Northwestern University, Evanston, IL. Proquest Number: 10603427.

Rappaport, N., Alegria, M., Mulvaney-Day, N., & Boyle, B. (2008). Staying at the table: building sustainable community–research partnerships. Journal of Community Psychology, 36(6), 693-701.

Redfield, E. & Conron, K.J. (co-first authors), Tentindo, W., Browning, E. (2023). Prohibiting GenderAffirming Medical Care for Youth. The Williams Institute, UCLA, Los Angeles, CA.

Reisner SL, Vetters R, White JM, et al. Laboratory-confirmed HIV and sexually transmitted infection seropositivity and risk behavior among sexually active transgender patients at an adolescent and young adult urban community health center. AIDS Care. 2015;27(8):1031-1036.

Reisner SL, White Hughto JM, Pardee D, Sevelius J. Syndemics and gender affirmation: HIV sexual risk in female-to-male trans masculine adults reporting sexual contact with cisgender males. Int J STD AIDS. 2016;27(11):955-966.

Reuter TR, Newcomb ME, Whitton SW, Mustanski B. Intimate Partner Violence Victimization in LGBT Young Adults: Demographic Differences and Associations with Health Behaviors. Psychol Violence. 2017;7(1):101-109.

Reuter, T.R., Newcomb, M.E., Whitton, S.W. and Mustanski, B. 2017. Intimate partner violence victimization in LGBT young adults: Demographic differences and associations with health behaviors. Psychology of Violence. (2017). DOI:https://doi.org/10.1037/vio0000031.

Romano, A. (2018, April 13). A new law intended to curb sex trafficking threatens the future of the internet as we know it. Vox. Retrieved April 5, 2022, from https://www.vox.com/culture/2018/4/13/17172762/fosta-sesta-backpage-230-internet-freedom

Rosenberg, S., & Tilley, P. M. (2021). 'A point of reference': the insider/outsider research staircase and transgender people's experiences of participating in trans-led research. Qualitative Research, 21(6), 923-938.

Ruberg, B., & Ruelos, S. (2020). Data for queer lives: How LGBTQ gender and sexuality identities challenge norms of demographics. Big Data & Society, 7(1), 2053951720933286.

Ryan, S., Yip, J., Stieff, M. and Druin, A. 2013. Cooperative inquiry as a community of practice. Computer-Supported Collaborative Learning Conference, CSCL (2013).

S. Ahmed. 2012. On being included: Racism and diversity in institutional life. Sociological Research Online. Duke University Press Books.

S. Bardzell and J. Bardzell. 2011. Towards a feminist HCI methodology: Social science, feminism, and HCI. In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems. 675–684. DOI:https://doi.org/10.1145/ 1978942.1979041

S. Costanza-Chock. 2018. Design justice: Towards an intersectional feminist framework for design theory and practice. In Proceedings of the Design Research Society 2018. DOI:https://ssrn.com/abstract=3189696

S. D. Grady, P. J. Wisniewski, R. Metoyer, P. Gibbs, K. Badillo-Urquiola, S. Elsayed-Ali, and E. Yafi. 2020. Addressing institutional racism within initiatives for SIGCHI's diversity and inclusion. Interactions. Retrieved from https: //interactions.acm.org/blog/view/addressing-institutional-racism-within-initiatives-for-sigchis-diversity-an.

S. D. Grieb, M. M. Eder, K. C. Smith, K. Calhoun, and D. Tandon. 2015. Qualitative research and community-based participatory research: Considerations for effective dissemination in the peer-reviewed literature. Progress in Community Health Partnerships: Research, Education, and Action 9, 2 (2015), 275–282. DOI:https://doi.org/10.1353/cpr. 2015.0041

S. Daley, D. L. Wingard, and V. Reznik. 2006. Improving the retention of underrepresented minority faculty in academic medicine. Journal of the National Medical Association 98, 9 (2006), 1435–1440.

S. De Leeuw, E. S. Cameron, and M. L. Greenwood. 2012. Participatory and community-based research, indigenous geographies, and the spaces of friendship: A critical engagement. Canadian Geographer 56, 2 (2012), 180–194. DOI:https://doi.org/10.1111/j.1541-0064.2012.00434.x

S. Erete, A. Israni, and T. Dillahunt. 2018. An intersectional approach to designing in the margins. Interactions 25, 3 (2018), 66–69. DOI:https://doi.org/10.1145/3194349

S. Erete, Y. A. Rankin, and J. O. Thomas. 2020. I can't breathe: Reflections from black women in CSCW and HCI. Proceedings of the ACM on Human-Computer Interaction 4, CSCW3 (2020), Article 234, 23 pages. DOI:https://doi.org/ 10.1145/1122445.1122456

S. G. Harding. 2004. The feminist standpoint theory reader. In The Feminist Standpoint Theory Reader: Intellectual and Political Controversies. Routledge.

S. Ghoshal and A. Bruckman. 2019. The role of social computing technologies in grassroots movement building. ACM Transactions on Computer-Human Interaction 26, 3 (2019), Article 18, 36 pages. DOI:https://doi.org/10.1145/3318140

S. Harding. 1992. Rethinking standpoint epistemology: What is "strong objectivity?" The Centennial Review 36, 3 (1992), 437–470. Retrieved December 23, 2020 from http://www.jstor.org/stable/23739232

S. Hardouin, T. W. Cheng, E. L. Mitchell, S. J. Raulli, D. W. Jones, J. J. Siracuse, and A. Farber. 2020. Prevalence of unprofessional social media content among young vascular surgeons. Journal of Vascular Surgery 72, 2 (2020), 667–671.

S. K. Kane, J. P. Bigham, and J. O. Wobbrock. 2008. Slide rule: Making mobile touch screens accessible to blind people using multi-touch interaction techniques. In Proceedings of the 10th International ACM SIGACCESS Conference on Computers and Accessibility (ASSETS'08). 73–80. DOI:https://doi.org/10.1145/1414471.1414487

S. Kolovson, A. Pratap, J. Duffy, R. Allred, S. A. Munson, and P. A. Areán. 2020. Understanding participant needs for engagement and attitudes towards passive sensing in remote digital health studies. In Proceedings of the 14th EAI International Conference on Pervasive Computing Technologies for Healthcare (PervasiveHealth'20). DOI:https: //doi.org/10.1145/3421937.3422025

S. L. Erete. 2015. Engaging around neighborhood issues: How online communication affects offline behavior. In Proceedings of the 2015 ACM International Conference on Computer-Supported Cooperative Work and Social Computing (CSCW'15). 1590–1601. DOI:https://doi.org/10.1145/2675133.2675182

S. Linton. 1998. Claiming Disability: Knowledge and Identity. NYU Press. DOI:https://doi.org/10.5860/choice.35-6303

S. P. Wyche and L. L. Murphy. 2012. "Dead china-make" phones off the grid: Investigating and designing for mobile phone use in rural Africa. In Proceedings of the Designing Interactive Systems Conference (DIS'12). 186–195. DOI:https: //doi.org/10.1145/2317956.2317985

S. P. Wyche, M. Densmore, and B. S. Geyer. 2015. Real mobiles: Kenyan and Zambian smallholder farmers? Current attitudes towards mobile phones. In Proceedings of the 7th International Conference on Information and Communication Technologies and Development. Article 9, 1–10. DOI:https://doi.org/10.1145/2737856.2738013

S. Ryan, J. Yip, M. Stieff, and A. Druin. 2013. Cooperative inquiry as a community of practice. ComputerSupported Collaborative Learning Conference 2, CSCL (2013), 145–148. Retrieved from http://bigyipper.com/wpcontent/uploads/2010/11/CSCL2013_ShortPaper_Submission.pdf.

S. Schalk. 2013. Coming to claim crip: Disidentification with/in disability studies. Disability Studies Quarterly 33, 2 (2013). 10.18061/dsq.v33i2.3705

S. Sultana, F. Guimbretière, P. Sengers, and N. Dell. 2018. Design within a patriarchal society: Opportunities and challenges in designing for rural women in Bangladesh. In Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems. Paper 536, 1–13. DOI:https://doi.org/10.1145/3173574.3174110

S. Villenas. 1996. The colonizer/colonized Chicana ethnographer: Identity, marginalization, and co-optation in the field. Harvard Educational Review 66, 4 (1996), 711–732. DOI: https://doi.org/10.17763/haer.66.4.3483672630865482

S. Wendell. 2016. Unhealthy disabled: Treating chronic illnesses as disabilities. In The Disability Studies Reader (5th ed.). Routledge. https://doi.org/10.1111/j.1527–2001.2001.tb00751.x

S. Wyche, T. R. Dillahunt, N. Simiyu, and S. Alaka. 2015. “If god gives me the chance I will design my own phone”: Exploring mobile phone repair and postcolonial approaches to design in rural Kenya. In Proceedings of the 2015 ACM International Joint Conference on Pervasive and Ubiquitous Computing (UbiComp’15). 463–473. DOI:https://doi.org/ 10.1145/2750858.2804249

Sabin, J., Weibel, N., Casanova-Perez, R., Emmenegger, C., Pratt, W., Lane, C., ... & Hartzler, A. (2021, June). Developing a Healthcare Equity Tool: Combining Technology and Stakeholder Engagement to Uncover Hidden Bias in Patient-Provider Interactions. In 2021 Annual Research Meeting. AcademyHealth.

Satcher, D. (2005). Methods in community-based participatory research for health. John Wiley & Sons.

Savage, N. (2020). How AI is improving cancer diagnostics. Nature, 579(7800), S14-S14.

Scheim AI, Travers R. Barriers and facilitators to HIV and sexually transmitted infections testing for gay, bisexual, and other transgender men who have sex with men. AIDS Care. 2017;29(8):990-995.

Scheim, A. I., Appenroth, M. N., Beckham, S. W., Goldstein, Z., Grinspan, M. C., Keatley, J. G., & Radix, A. (2019). Transgender HIV research: nothing about us without us. The Lancet HIV, 6(9), e566-e567.

Scheuerman, M.K., Branham, S.M. and Hamidi, F. 2018. Safe spaces and safe places: Unpacking technology-mediated experiences of safety and harm with transgender people. Proceedings of the ACM on Human-Computer Interaction. (2018). DOI:https://doi.org/10.1145/3274424.

Schimmel-Bristow, A. and Ahrens, K.R. 2018. Technology use among special populations. Technology and Adolescent Mental Health.

Schimmel-Bristow, A., Haley, S.G., Crouch, J.M., Evans, Y.N., Ahrens, K.R., McCarty, C.A. and Inwards-Breland, D.J. 2018. Youth and caregiver experiences of gender identity transition: A qualitative study. Psychology of Sexual Orientation and Gender Diversity. (2018). DOI:https://doi.org/10.1037/sgd0000269.

Sevelius, J.M., Keatley, J.A., Calma, N. and Arnold, E. 2016. 'I am not a man': Trans-specific barriers and facilitators to PrEP acceptability among transgender women. Global Public Health. 11, 7–8 (2016), 1060–1075. DOI:https://doi.org/10.1080/17441692.2016.1154085.

Sharma A, Kahle E, Todd K, Peitzmeier S, Stephenson R. Variations in Testing for HIV and Other Sexually Transmitted Infections Across Gender Identity Among Transgender Youth. Transgend Health. 2019;4(1):46-57.

Shostack, A. 2014. Threat Modeling: Designing for Security. John Wiley & Sons.

Simonsen, J., Karasti, H., & Hertzum, M. (2020). Infrastructuring and participatory design: Exploring infrastructural inversion as analytic, empirical and generative. Computer Supported Cooperative Work (CSCW), 29, 115-151.

Singer, N. 2018. "Grindr sets off privacy firestorm after sharing users' H.I.V.-status data," New York Times (3 April), at https://www.nytimes.com/2018/04/03/technology/grindr-sets-off-privacy-firestorm-after-sharing-users-hiv-status-data.html, accessed 5 September 2020.

Slupska, J., Cho, S., Begonia, M., Abu-Salma, R., Prakash, N., & Balakrishnan, M. (2022). " They Look at Vulnerability and Use That to Abuse You": Participatory Threat Modelling with Migrant Domestic Workers. In 31st USENIX Security Symposium (USENIX Security 22) (pp. 323-340).

Slupska, J., Dawson Duckworth, S. D., Ma, L., & Neff, G. (2021, May). Participatory threat modelling: Exploring paths to reconfigure cybersecurity. In extended abstracts of the 2021 CHI conference on human factors in computing systems (pp. 1-6).

Smith LR, Yore J, Triplett DP, et al. Impact of Sexual Violence Across the Lifespan on HIV Risk Behaviors Among Transgender Women and Cisgender People Living With HIV. J Acquir Immune Defic Syndr. 2017;75(4):408-416.

Smith, J. 2013. Talking Back to Facebook: The Common Sense Guide to Raising Kids in the Digital Age. Library Journal. (2013).

Smith, L.T. 2012. Decolonizing Methodologies: Research and Indigenous Peoples. Zed Books. 2nd Ed. pg 10.

Spiel, K., Keyes, O., Walker, A. M., DeVito, M. A., Birnholtz, J., Brulé, E., ... & Kannabiran, G. (2019, May). Queer (ing) HCI: Moving forward in theory and practice. In Extended Abstracts of the 2019 CHI Conference on Human Factors in Computing Systems (pp. 1-4).

Stanger-Hall, K.F. and Hall, D.W. 2011. Abstinence only education and teen pregnancy rates: Why we need comprehensive sex education in the U.S. PLoS ONE. (2011). DOI:https://doi.org/10.1371/journal.pone.0024658.

Stark, L., King, J., Page, X., Lampinen, A., Vitak, J., Wisniewski, P., ... & Good, N. (2016, May). Bridging the gap between privacy by design and privacy in practice. In Proceedings of the 2016 CHI Conference Extended Abstracts on Human Factors in Computing Systems (pp. 3415-3422).

Starks, D. L., Dillahunt, T., & Haimson, O. L. (2019, June). Designing technology to support safety for transgender women & non-binary people of color. In Companion Publication of the 2019 on Designing Interactive Systems Conference 2019 Companion (pp. 289-294).

Sterzing PR, Ratliff GA, Gartner RE, McGeough BL, Johnson KC. Social Ecological Correlates of Polyvictimization among a National Sample of Transgender, Genderqueer, and Cisgender Sexual Minority Adolescents. Child Abuse Negl. 2017;67:1-12.

Stroh, D. P. (2015). Systems thinking for social change: A practical guide to solving complex problems, avoiding unintended consequences, and achieving lasting results. Chelsea Green Publishing

Sullivan, N. (2003). A critical introduction to queer theory. NYU Press.

Suman, A. B., Heyen, N. B., & Micheli, M. (2023). Reimagining health services provision for neglected groups: The “personalization from below” phenomenon. Frontiers in sociology, 8, 1052215.

Sweet, P. L. (2020). Who Knows? Reflexivity in Feminist Standpoint Theory and Bourdieu. Gender & Society, 34(6), 922–950.

T. Bratteteig and I. Wagner. 2012. Disentangling power and decision-making in participatory design. In Proceedings of the 12th Participatory Design Conference: Research Papers (PDC’12). 41–50. DOI: https://doi.org/10.1145/2347635. 2347642

T. C. Veinot, J. S. Ancker, H. Cole-Lewis, E. D. Mynatt, A. G. Parker, K. A. Siek, and L. Mamykina. 2019. Leveling up: On the potential of upstream health informatics interventions to enhance health equity. Medical Care 57, 6 (2019), S108–S114. DOI:10.1097/MLR.0000000000001032

T. Dillahunt, J. Mankoff, and E. Paulos. 2010. Understanding conflict between landlords and tenants: Implications for energy sensing and feedback. In Proceedings of the 2010 ACM Conference on Ubiquitous Computing (UbiComp'10). 149–158. DOI: https://doi.org/10.1145/1864349.1864376

T. Gillespie. 2018. Custodians of the Internet: Platforms, Content Moderation, and the Hidden Decisions that Shape Social Media. Yale University Press.

T. R. Dillahunt and T. C. Veinot. 2018. Getting there: Barriers and facilitators to transportation access in underserved communities. ACM Transactions on Computer-Human Interaction 25, 5 (2018), Article 29. DOI:https://doi.org/10.1145/ 3233985

Tad Hirsch and John Henry. 2005. TXTmob: Text messaging for protest swarms. In Proceedings of the CHI'05 Extended

The Trevor Project. (2021). 2021 National Survey on LGBTQ Youth Mental Health. West Hollywood, California: The Trevor Project. For additional information please contact: Research@TheTrevorProject.org

Themba-Nixon M, Minkler M, Freudenberg N. The role of CBPR in policy advocacy. In: Minkler M, Wallerstein N, eds. Community Based Participatory Research for Health: From Process to Outcomes. 2nd ed. San Francisco, CA: Jossey-Bass; 2008:307–322.

Theoretical Approachesto Diversity and Taxonomy in the Technical Communication

Tseng, E., Sabet, M., Bellini, R., Sodhi, H. K., Ristenpart, T., & Dell, N. (2022, April). Care infrastructures for digital security in intimate partner violence. In Proceedings of the 2022 CHI Conference on Human Factors in Computing Systems (pp. 1-20).

Turner CM, Santos GM, Arayasirikul S, Wilson EC. Brief Report: Psychosocial Predictors of Engagement in Sexual Risk Behavior Among Trans*female Youth Aged 16-24 Years in San Francisco. J Acquir Immune Defic Syndr. 2017;74(3):258-264.

Udoewa, V. (2022). Radical Participatory Design: Awareness of Participation. Journal of Awareness-Based Systems Change, 2(2), 59-84.

U.S. Centers for Disease Control and Prevention. "The Tuskegee Timeline". U.S. Public Health Service Syphilis Study at Tuskegee. Archived from the original on May 10, 2019. Retrieved May 3, 2023. It was called the 'Tuskegee Study of Untreated Syphilis in the Negro Male.'

V. Braun and V. Clarke. 2006. Using thematic analysis in psychology. Qualitative Research in Psychology 3, 2 (2006), 77–101. DOI:https://doi.org/10.1191/1478088706qp063oa

V. Braun and V. Clarke. 2019. To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. Qualitative Research in Sport, Exercise and Health 13, 2 (2019), 201–216. DOI:https://doi.org/10.1080/2159676X.2019.1704846

Vacca, R. 2019. Brokering data: Co-designing technology with latina teens to support communication with parents: Leveraging cultural practices of Latinx youth through co-design. Proceedings of the 18th ACM International Conference on Interaction Design and Children, IDC 2019 (2019).

Vasquez VB, Lanza D, Hennessey-Lavery S, Facente S, Halpin HA, Minkler M. Addressing food security through public policy action in a community-based participatory research partnership. Health Promot Pract. 2007;8(4):342–349.

Vasquez VB, Minkler M, Shepard P. Promoting environmental health policy through community based participatory research: a case study from Harlem, New York. J Urban Health. 2006;83(1):101–110.

Veale J, Watson RJ, Adjei J, Saewyc E. Prevalence of Pregnancy Involvement Among CanadianTransgender Youth and its Relation to Mental Health, Sexual Health, and Gender Identity. Int J Transgend. 2016;17(3-4):107-113.

Veinot, T. C., Mitchell, H., & Ancker, J. S. (2018). Good intentions are not enough: how informatics interventions can worsen inequality. Journal of the American Medical Informatics Association, 25(8), 1080-1088.

Veinot, T.C., Ancker, J.S., Cole-Lewis, H., Mynatt, E.D., Parker, A.G., Siek, K.A. and Mamykina, L. 2019. Leveling Up: On the Potential of Upstream Health Informatics Interventions to Enhance Health Equity. Medical Care.

Veseli, F., Olvera, J. S., Pulls, T., & Rannenberg, K. (2019, April). Engineering privacy by design: lessons from the design and implementation of an identity wallet platform. In Proceedings of the 34th ACM/SIGAPP Symposium on Applied Computing (pp. 1475-1483).

W. D. Mignolo. 2018. What does it mean to decolonize? In On Decoloniality. W. D. Mignolo and C. E. Walsh (Eds.), Duke University Press, 105–134.

W. J. Orlikowski and J. J. Baroudi. 1991. Studying information technology in organizations: Research approaches and assumptions. Information Systems Research 2, 1 (1991), 1–84. DOI:https://doi.org/10.1287/isre.2.1.1

Walsh, G., Foss, E., Yip, J. and Druin, A. 2013. FACIT PD: A framework for analysis and creation of intergenerational techniques for participatory design. Conference on Human Factors in Computing Systems - Proceedings (2013).

Wang, S., Moss, J. R., & Hiller, J. E. (2006). Applicability and transferability of interventions in evidence-based public health. Health promotion international, 21(1), 76-83.

Wang, Y., & Kosinski, M. (2018). Deep neural networks are more accurate than humans at detecting sexual orientation from facial images. Journal of personality and social psychology, 114(2), 246.

Weinstein, E. R., Herrera, C. M., Pla Serrano, L., Martí Kring, E., & Harkness, A. (2023). Promoting health equity in HIV prevention and treatment research: a practical guide to establishing, implementing, and sustaining community advisory boards. Therapeutic advances in infectious disease, 10, 20499361231151508.

Wesp, L. M., Malcoe, L. H., Elliott, A., & Poteat, T. (2019). Intersectionality research for transgender health justice: A theory-driven conceptual framework for structural analysis of transgender health inequities. Transgender health, 4(1), 287-296.

Whitton SW, Newcomb ME, Messinger AM, Byck G, Mustanski B. A Longitudinal Study of IPV Victimization Among Sexual Minority Youth. J Interpers Violence. 2016.

Wilson EC, Garofalo R, Harris DR, Belzer M. Sexual risk taking among transgender male-to-female youths with different partner types. Am J Public Health. 2010;100(8):1500-1505.

Wisniewski, P., Xu, H., Rosson, M. B., & Carroll, J. M. (2017, February). Parents just don't understand: Why teens don't talk to parents about their online risk experiences. In Proceedings of the 2017 ACM conference on computer supported cooperative work and social computing (pp. 523-540).

Wisniewski, P., Xu, H., Rosson, M. B., Perkins, D. F., & Carroll, J. M. (2016, May). Dear diary: Teens reflect on their weekly online risk experiences. In Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems (pp. 3919-3930).

Wong-Villacres, M., DiSalvo, C., Kumar, N., & DiSalvo, B. (2020, April). Culture in action: Unpacking capacities to inform assets-based design. In Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems (pp. 1-14).

Wong-Villacres, M., Erete, S., Gautam, A., Ismail, A., Kumar, N., Pei, L., ... & Motti, V. G. (2022). Elevating strengths and capacities: the different shades of assets-based design in HCI. Interactions, 29(5), 28-33.

Wong-Villacres, M., Gautam, A., Tatar, D., & DiSalvo, B. (2021). Reflections on assets-based design: A journey towards a collective of assets-based thinkers. Proceedings of the ACM on Human-Computer Interaction, 5(CSCW2), 1-32.

Woodman, R.W., Sawyer, J.E. and Griffin, R.W. 1993. Toward a Theory of Organizational Creativity. Academy of Management Review. (1993). DOI:https://doi.org/10.5465/amr.1993.3997517.

Y. A. Rankin and J. O. Thomas. 2019. Straighten up and fly right: Rethinking intersectionality in HCI research. Interactions 26, 6 (2019), 64–68. DOI: https://doi.org/10.1145/3363033

Y. A. Rankin, J. O. Thomas, and N. M. Joseph. 2020. Intersectionality in HCI: lost in translation. Interactions 27, 5 (2020), 68–71. DOI:https://doi.org/10.1145/3416498

Y. B. Shrinivasan, M. Jain, D. P. Seetharam, A. Choudhary, E. Huang, T. Dillahunt, and J. Mankoff. 2013. Deep conservation in urban India and its implications for the design of conservation technologies. In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems. 1969–1978. DOI: https://doi.org/10.1145/2470654.2466261

Yang, M. (2022, March 10). Idaho bill that criminalizes medical trans youth treatments passes house. The Guardian. Retrieved March 25, 2022, from https://www.theguardian.com/us-news/2022/mar/10/idaho-bill-trans-youth-treatment-ban-passes-house

Yip, J. C., Sobel, K., Pitt, C., Lee, K. J., Chen, S., Nasu, K., & Pina, L. R. (2017). Examining adult-child interactions in intergenerational participatory design. Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems, 5742–5754.

Zuboff, S. (2019). The age of surveillance capitalism: The fight for a human future at the new frontier of power: Barack Obama's books of 2019. Profile books.