

Designing Technology to Support Health Information and Services Seeking for the LGBTQIA+ Community

by

Taylor Schell Martinez

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Taylor Schell Martinez

tshell@umich.edu

ORCID iD: [0000-0002-7888-135X](https://orcid.org/0000-0002-7888-135X)

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The undersigned certify that they have read and recommend to the Faculty of Graduate Studies for acceptance, a thesis entitled “Designing Technology to Support Health Information and Services Seeking for the LGBTQIA+ Community” submitted by Taylor Schell Martinez in partial fulfillment of the requirements for the degree of Master of Science.



Advisor, Dr. Charlotte Tang

Department of Computer Science

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Dedication

To my dear family (Leroy, Rosario, and Diomante) who supported and encouraged me through this crazy journey, thank you - only with your help was I able to make it! Thank you, Rosa, for cheering me on at every step, teaching me how to keep my imposter syndrome in check, inspiring me as a person, and proofreading my writing. I could not have done this without your encouragement, red ink, and confidence in me that I could succeed!! Dio, thank you for being my kind determined, hardworking, and sweet child – your grace and kindness inspire me to be a better person. Leroy, thank you for loving me and being my shoulder to cry on.

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List of Abbreviations

ARV: antiretroviral drugs

GH: general health

GHI: general health information

HP: healthcare providers

HPV: Human papillomavirus infection

MH: mental health

MHP: mental health professional

PCP: primary care provider

PEP: post-exposure prophylaxis

PREP: pre-exposure prophylaxis

QH: LGBTQIA+ health

QHI: LGBTQIA+ health information

SH: sexual health

SHI: sexual health information

VA: voice assistant

Abstract

Many LGBTQIA+ individuals' resort to seeking health information and services online and through other digital sources due to their fear of discrimination and stigma. Thus, the current research investigates how LGBTQIA+ individuals use technology to find health information, seek health services, and interact with their healthcare providers. Online surveys and Zoom interviews were conducted with people over 18 years old, who self-identify as LGBTQIA+, to acquire a better understanding of their health information seeking behaviors, their interactions with healthcare providers, and the technologies they use to manage their health and well-being. In particular, we examined the impacts of the recent COVID-19 pandemic on their health-related behaviors. We also investigated if healthcare providers were collecting LGBTQIA+ identity information and if so, how they were utilizing that information.

Our research aims to answer these questions: Do digital sources provide those who identify as LGBTQIA+ with reliable, accurate, and inclusive health information and services that cover all their needs as LGBTQIA+ individuals? Could collecting and using LGBTQIA+ identity information as part of the electronic medical record improves interactions with healthcare providers, provide more holistic healthcare, and increase accessibility to health information and services for the LGBTQIA+ community? Could new or improved technologies help enrich LGBTQIA+ individuals' health information seeking experiences and access to health services, as well as facilitate patient-provider interactions? Our goal is to identify the challenges and barriers LGBTQIA+ individuals experienced when seeking health information and accessing health care services. The findings of our study will be used to inform the design of new or improved technological solutions to alleviate the identified challenges.

1 INTRODUCTION

The Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, and Asexual (LGBTQIA+) community has historically struggled to access LGBTQIA+ related health information, services, and care. Despite the gradually growing acceptance, the LGBTQIA+ community still experiences exclusions, prejudices, and discrimination when seeking health information and services [1, 2, 3, 4, 5, 6]. Our study sought to investigate if the LGBTQIA+ community's healthcare services and information needs are being met, what barriers or challenges LGBTQIA+ individuals may experience while seeking information and how their experience could be improved through new or improved technologies. It also sought to investigate the impact the COVID-19 pandemic has had as well as the affect that discrimination towards the LGBTQIA+ community has on the LGBTQIA+ individual's ability to find health services and information and how the patient-provider relationship could be improved?

Health disparities between LGBTQIA+ individuals and the general population have been well documented in the literature (e.g., references). Long before COVID-19, the LGBTQIA+ community, "especially youth, reported higher rates of anxiety, depression, suicidal ideation and non-suicidal self-injury" [7]. The transgender community is particularly impacted, with nearly 50% reported postponing health care because they were unable to afford it [8]. Studies have shown that despite recommendations from the Institute of Medicine, as well as over 150 other health institutions in the United States to collect and document gender identity and sexual orientation information in electronic health records, this information is still not uniformly collected causing inaccuracies in statistics and missed opportunities to "assess, track, and combat

population-level health disparities” [8, 9, 10, 11]. Most health technologies and professionals still only ask individuals to identify as one of the binary sex classifications, male or female, and assume heterosexuality, instantly eliminating the appropriate options for over 10 million people in the United States alone who do not fit into those constraints [12]. This creates a void of health information for and about LGBTQIA+ communities.

Given the clear lack of inclusion of LGBTQIA+ individuals within the medical setting and health records, they expressed that they often feel invisible. Thus, many internalize and interpret the failure to collect sexual orientation and gender identity information as a way that healthcare providers reinforce heteronormative, cisgender societal norms or hold possible negative attitudes or beliefs towards the LGBTQIA+ community itself [7]. The LGBTQIA+ community often experiences discrimination when seeking health information and care. Previous research has shown that nearly 40% of trans¹ people reported having at least one negative experience with a healthcare provider including “being refused treatment, verbal harassment,

¹ Being *transgender* refers to a person whose gender is different than the sex they were assigned at birth, as does *trans* [2]. Trans and transgender are often used interchangeably, as it is throughout our research, but we quickly found out they are not interchangeable for many who identify as only one and not the other. Transgender is often used to refer those who identify as the opposite gender as they were assigned at birth. Trans is often used to describe those who do not necessarily fit the sex they were assigned at birth but do not feel they identify as the opposite gender either, they tend to be non-binary, genderfluid, etc. Trans can also be used as an umbrella term to include both trans and transgender individuals. In our research use trans as an umbrella term but distinguish when do so versus using it as a specific term to minimize confusion.

physical or sexual assault or having to teach the provider about transgender health in order to get appropriate care”, 28% had postponed care due to discrimination and 28% had experienced harassment in the medical settings due to their gender identity [5, 8]. Within the transgender community, those of color experience even harsher disparities when attempting to find healthcare providers who are both LGBTQIA+ friendly and not racist, with feelings that they would be treated better if they were white or cisgender [13].

Despite being overlooked by technology designers, digital sources and online channels are still the second most popular places for LGBTQIA+ people to seek health information after healthcare providers due to fears of discrimination and stigma [12, 14, 15]. The lack of a more robust LGBTQIA+ identification system in health technologies, healthcare providers, computer scientists and designers alike continue to ignore a crucial LGBTQIA+ demographic while simultaneously fueling disparity and discrimination by creating inaccuracies in health information technologies and their resulting data sets. If healthcare providers, technologies and applications do not ask or know how to ask appropriately, how can they possibly provide accurate health information and/or collect accurate data about an individual?

This research study aims to identify the challenges and barriers LGBTQIA+ individuals experienced when seeking health information and accessing health care services so that they can be addressed in the future. The findings can inform the design of new or improved technological solutions to alleviate the identified challenges. The ultimate goal of this research is to improve health information, services, and technologies accessibility and inclusivity for the LGBTQIA+ community.

1.1 Problem Statement

The purpose of this qualitative study was to identify, through the perceptions and experiences of LGBTQIA+ individuals, the challenges and barriers they experience when seeking health information and services and how they could be alleviated through improved or new technologies to improve care for the LGBTQIA+ community.

1. Is the Internet serving the LGBTQIA+ community's health needs? The Internet has long been considered a safe, accessible, and private way to find health information and services by many LGBTQIA+ individuals of every age category [16, 17, 18, 19, 20, 12, 21]. My research investigated if digital sources provide those who identify as LGBTQIA+ with reliable, accurate, and inclusive health information and services that cover all their needs as LGBTQIA+ individuals?

2. Would collecting and using LGBTQIA+ identifiers improve LGBTQIA+ individuals' health care? Could collecting and using LGBTQIA+ identity information as part of the electronic medical record, as suggested by many health institutions, improve interactions with healthcare providers, provide more holistic healthcare, and increase accessibility to health information and services for the LGBTQIA+ community? What would be the best approach to collecting this information?

3. Can technology improve healthcare for the LGBTQIA+ community? Could new or improved technologies help enrich LGBTQIA+ individuals' health information seeking experiences and access to health services, as well as facilitate patient-provider interactions?

1.2 Significance of the study

This research study used user-centered design approach to inform the design of health information technologies to accommodate the full spectrum of LGBTQIA+ identities and provide the most accurate health information and care for all involved: the healthcare recipients, providers, researchers, and designers. This study aims to identify the current challenges and barriers LGBTQIA+ individuals face when seeking health information and areas where their needs are not met. The findings will thus help improve care for the LGBTQIA+ community.

Our study also investigated the COVID-19 pandemics' impact on how LGBTQIA+ individuals use technology to find health information, seek health services, and interact with their medical care professionals. Using this information will allow any disparities to be reconciled and to address shortcomings, challenges, and barriers prior to another natural disaster occurring to foster better healthcare access for the LGBTQIA+ community.

Our research sought to better understand how LGBTQIA+ identity is used in relation to the electronic health record (EHR) and the healthcare setting. We investigated if healthcare providers are inquiring about the different facets of an individual's LGBTQIA+ identity and if they are incorporating LGBTQIA+ identities into their patient's healthcare as recommended by many health institutions. Knowing if this information is being collected and how it is being used can help improve or show how it has improved LGBTQIA+ health services and information. The goal of this research is to use our findings to improve health information, services, and technologies accessibility and inclusivity for the LGBTQIA+ community.

1.3 Overview of Thesis

Chapter 2 provides background information of the fundamental issue of this research: is LGBTQIA+ identity information being collected and used by healthcare providers to improve health information and services access for LGBTQIA+ individuals? Previous research shows that LGBTQIA+ identity information is not often collected for the electronic health record data, despite medical associations encouraging its use, and the lack of doing so further fuels the disparities already experienced.

In Chapter 3, the health information seeking strategies used by LGBTQIA+ participants, both survey respondents and interviewees, and the preferred resources they used for different types of health information is investigated. The productivity and accuracy of the health information is also discussed.

In Chapter 4 the impact the COVID-19 pandemic had on survey respondents' health information and services seeking is discussed, as well as if their previous experience using digital health sources helped them navigate the pandemic.

In Chapter 5 the participants experiences and insight in relation to collecting LGBTQIA+ identity information for the electronic health record and its impact on healthcare is discussed. If participants feel their LGBTQIA+ identity is respected, acknowledged, and addressed by a knowledgeable health care provider is also identified. The current methods used to collect this information, the information being collected and how it is being used are further discussed as well as interviewees preferred collection methods and approach to the collecting LGBTQIA+ identifiers.

Chapter 6 concludes with limitations of the study, a summary of the problems and findings, the research contributions, and future works.

2 REVIEW OF THE LITERATURE

Our study sought to investigate if the LGBTQIA+ community's healthcare services and information needs are being met, what barriers or challenges LGBTQIA+ individuals may experience while seeking information and how their experience could be improved through new or improved technologies. It also sought to investigate the impact the COVID-19 pandemic has had on the already well documented health disparities as well as the one discrimination has on the LGBTQIA+ community's ability to find health services and information and how the patient-provider relationship could be improved?

In Chapter 2, a review of the literature presents the current findings on the importance and impact of healthcare providers, institutions and technologies collecting and using LGBTQIA+ identity information for health-related interactions. Previous research has shown that a lack of inclusive design negatively impacts health accessibility for LGBTQIA+ individuals. While LGBTQIA+ inclusivity improves relationships with health providers and optimizes care by underpinning health care customization, not collecting LGBTQIA+ identity information compounds health data inaccuracies and inaccessibilities. Simply using a more inclusive set of LGBTQIA+ identifiers can normalize the collection and interaction with such identities while reducing disparities and discrimination experienced by the LGBTQIA+ community. It is imperative for health care that LGBTQIA+ identity information be collected and used.

2.1 Lack of Inclusive Design Impacts LGBTQIA+ Individual Health Accessibility

The Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, and Asexual (LGBTQIA+) community has historically struggled to access LGBTQIA+ related health information, services, and care, forcing them to often seek alternative sources of health care information. Despite the gradually growing acceptance, the LGBTQIA+ community still experiences exclusions, prejudices, and discrimination when seeking health information and services [1, 2, 3, 4, 5, 6]. The Internet has long been considered a safe, accessible, and private way to find health information and services by many LGBTQIA+ individuals of every age category [16, 17, 18, 19, 20, 12, 21], but is it serving the LGBTQIA+ community's healthcare needs? Designing health technologies to accommodate the full spectrum of LGBTQIA+ identities would provide the most accurate health information and care for all involved: the health seekers, providers, researchers, and designers. If healthcare providers, technologies and applications do not ask, how can they provide accurate health information and/or collect accurate data about an individual?

Despite being overlooked by technology designers, digital sources, and online channels are still the second most popular places for LGBTQIA+ people to seek health information after healthcare providers due to fears of discrimination and stigma [12, 14, 15]. Most health technologies and professionals still only ask individuals to identify as one of the binary sex classifications, male or female, and assume heterosexuality, instantly eliminating the appropriate options for over 10 million people in the United States alone who do not fit into those constraints [12]. This creates a void of health information for and about LGBTQIA+ communities. However, due to the lack of a more robust LGBTQIA+ identification system, computer scientists and designers continue to ignore a crucial LGBTQIA+ demographic. It also creates inaccuracies

in health information technologies and their resulting data sets, which fuels disparity and discrimination.

Expanding the binary sex data field in medical records to include a more contemporary, robust, and accurate information set not only allows for the optimization of health care and information but may also help identify and reduce disparities and discriminatory behavior and foster inclusivity, further improving LGBTQIA+ health care. Collecting LGBTQIA+ identity related information would create more accurate data for analysis and algorithm creation, allowing more precise nuanced marketing while simultaneously expanding the ability to study the demographic more easily. Collecting LGBTQIA+ identity information would normalize the use and collection of this important information. By creating health technology that aids in the collection of LGBTQIA+ identity related information, we can make health more inclusive to the needs of all individuals while also making the data sets more valuable.

2.2 Increased LGBTQIA+ Inclusivity Improves Relationships and Optimizes Care

Sensitivity to appropriate vocabulary has been found to help create a positive relationship with the LGBTQIA+ community [22]. According to recent research, having gender-affirming identification may improve the mental health of non-binary individuals. Thus, proper gender identification in other areas especially those related to health may have the same positive impact. Similar findings also revealed that participants considered the ability to affirm their name, gender and pronouns as valuable aspects of digital technologies and highlighted these inputs as an important way to connect with game applications [21].

While collecting preferred name and pronouns can lead to an inclusive and affirming environment for LGBTQIA+ individuals, it generally creates improved inclusiveness among a broader audience including a variety of medical situations not limited to those involving

LGBTQIA+ individuals [8]. Nevertheless, LGBTQIA+ individuals do not necessarily want to be the center of design even though they wanted to be included in the design process [21]. Hence, when designing health technology for LGBTQIA+ individuals, it is important to allow them to affirm their identity so that they can feel connected to the technology. Currently, health technology rarely supports such identity inclusivity.

Collecting an expanded demographic set that includes LGBTQIA+ identifiers like sexual orientation, gender identity, sex at birth, current sex, pronouns, and preferred name is not about being politically or socially correct; it is about collecting medically relevant information to optimize health care. Since 2011, the Institute of Medicine (IOM), the Department of Health and Human Services' (HHS), the Office of National Coordination for Health Information Technology (ONCHIT) and the Joint Commission have recommended the collection of sexual orientation and gender identity information. Since then, 150 additional health researchers, providers and organizations have also publicly expressed their support for collecting the LGBTQIA+ identity information [8]. As the medical community has repeatedly stated, LGBTQIA+ identifiers are pertinent information directly related to quality health care.

2.3 Nuanced LGBTQIA+ Identification Underpins Health Care Customization

Without an opportunity to identify themselves, people who appear as one sex but identify as another may be given the wrong, or even harmful information, because basic health-related information was not collected or discussed. Collecting LGBTQIA+ identity related information allows healthcare providers to more effectively optimize health care for LGBTQIA+ populations. Recording the appropriate and needed data allows healthcare providers and technologies to screen for organ-specific health risks as well as lifestyle related risks that may have been missed without collecting LGBTQIA+ identity related information [8].

Not collecting LGBTQIA+ related information misses an opportunity for nuanced health care and information while diminishing accuracy. The medical field has stated LGBTQIA+ identity data being relevant and pertinent information for optimized health care. Thus, being researchers and designers, we should help facilitate a decade-old medical request by expanding our designs to collect valuable LGBTQIA+ identity related information.

2.4 Uncollected Identifiers Compound Health Data Inaccuracies

Many researchers discuss the difficulties of identifying members of the LGBTQIA+ community, leading to inaccuracies in data and care [8]. The difficulty of identifying LGBTQIA+ individuals may be due to a society's failure to request this information due to the historical stigma associated with being LGBTQIA+. The contemporary default style of design that asks individuals to only identify as male or female contributes to LGBTQIA+ people missing from the broad demographic data, hence the resulting inaccuracies. Health information systems that only collect binary sex and assume heterosexuality risk misclassifying over 4% of the population inaccurately [12].

In addition, it is extremely difficult, if not impossible, to identify uncollected identifiers and information. Therefore, such information should no longer be ignored. They are important information to be collected to provide not only optimized medical care but to reduce disparities. Being a member of the LGBTQIA+ community is something that should not have to be hidden, ignored, or uncomfortable to discuss especially in a medical setting, no more than any other health related issue.

2.5 Normalizing Collection of LGBTQIA+ Identifiers as Routine Practice

The design of health information technology impacts how and what health information is collected [14]. Currently, information related to a person's LGBTQIA+ identity is so rarely collected that many healthcare providers still feel hesitant and uncomfortable asking about it [14]. However, avoiding these important health-related questions renders healthcare providers unable to provide customized and proper health care and information to LGBTQIA+ populations. The resulting lack of information about a person's identity can create or compound health disparities, especially involving LGBTQIA+ related health issues. In fact, the communication gap between health seekers and providers allows myths and stereotypes to continue to dominate the LGBTQIA+ health discourse and permeate the health messages, making it an imperative gap to close [14]. The disconnect between medically needed LGBTQIA+ identifiers and those currently collected by health systems could be part of the problem, fueling some of the disparities and misinformation.

Using LGBTQIA+ identification questions daily could normalize the collection of information and possibly make healthcare providers and health seekers more "comfortable" discussing this important health topic. Thus, we can normalize the collection of LGBTQIA+ identity pertinent questions by including them in the design of health information technology and making them a routine practice to provide individualized tailored content.

2.6 Disparity Reduction with LGBTQIA+ Identity Collection

Mainstream media homogenizes LGBTQIA+ individuals into one group and focuses on their high rates of depression, self-harm, and suicide, further perpetuating these negative perceptions and focal points [22]. Even within the LGBTQIA+ community, different subcategories experience different health related disparities. For example, in Australia, over 72%

of transgender youth experience depression and/or anxiety and nearly 50% have attempted suicide [21]. In the USA, gay and bisexual men, despite being only 2% of the population, account for 50% of all new HIV diagnoses while 90% of the newly diagnosed HIV positive transgender people were African American or Latino [8, 15, 23].

Lesbian women also experienced health disparities due to healthcare professionals inadequately addressing their awareness of specific sexually transmittable diseases (STIs) and the need for regular cervical cancer screening due to increased prevalence in their community [24]. Without adequately designed health information technology, many lesbians and bisexual women are still unaware of the increased risks of bacterial and fungal STIs in their community and the importance of using barriers, cleaning sex toys, and discussing sexual health with their partners. This disjunction demonstrates “a significant communication gap between marginalized (lesbian and bisexual women) and dominant groups (practitioners)” that leads to unequal health outcomes [14].

In addition to the lack of LGBTQIA+-focused health information technology, LGBTQIA+ are often homogenized into an ever-expanding singular generic group, and again mostly focuses only on the negative aspects. High rates of STIs, suicide, depression, anxiety, bullying and a plethora of dating and social applications dominate the LGBTQIA+ discourse. Gathering LGBTQIA+ identity information via health information technology including sexual orientation, gender identification, sex at birth, and current sex enables managers and researchers to identify disparities in insurance coverage, access to care, diagnoses, treatments, public health initiative effectiveness and how LGBTQIA+ communities allocate resources [8].

2.7 Reducing Discrimination Through Identity Collection

Previous research showed that healthcare providers often used negative stereotypes or assumptions about the LGBTQIA+ community, contributing to the adverse experiences of LGBTQIA+ individuals [13]. As a result, myths propagate the dominant discourse and are also evident in health messages and experiences [14]. 82% of a survey respondents reported that they actively sought out LGBTQIA+ friendly healthcare providers in order to avoid hurtful assumptions and stressful interactions [13]. Not surprisingly, LGBTQIA+ individuals want to feel comfortable in the medical settings without fear of discrimination while having their full identity recognized and respected.

Although 99% of health institutes are trying to offer more inclusive health care services by including both sexual orientation and gender identity in their patient nondiscrimination policies, only 39% have practices and procedures to ensure the policies were enforced [22]. The collection of LGBTQIA+ identity information enables managers and researchers to identify discrimination that takes place in local health care institutions and allow institutions to address weaknesses and discrepancies identified in the policy and work practices [8]. Without knowledge of LGBTQIA+ identity information, monitoring the effectiveness of nondiscrimination policies is extremely difficult. In fact, LGBTQIA+ identity information can help identify areas, departments, or locations that need cultural competency and sensitivity training, making the data extremely valuable to human resources departments for customizing training and policies.

2.8 Fears Spur Online Health Information and Services Seeking

Discrimination and stigma fears lead many LGBTQIA+ individuals to seek out health information and services online and through other digital sources despite the design of these avenues not being inclusive of the community [25]. Prior to the pandemic, LGBTQIA+

individuals were found to more likely use the Internet to find health information, to fill a prescription, and to communicate with their health providers via email [18]. Seeking health information and services online provides a convenient, affordable delivery that also allows privacy and safety from fears of discrimination for many LGBTQIA+ individuals [21]. Online support from social media is commonly reported as a main support mechanism for LGBTQIA+ individuals [21]. LGBTQIA+ individuals even turn to the Internet when experiencing a crisis. For example, 44% of text messages sent to CrisisTextLine, a text message-based crisis support line, were from LGBTQIA+ individuals [12]. Multiple studies have shown a pre-pandemic heavy reliance on the Internet by LGBTQIA+ individuals when seeking health information and services through online LGBTQIA+ communities and social networks [16, 17, 18, 19, 20, 12, 21].

The lack of affordable, easily accessible, credible, and representative health information and services for the community without experiencing discrimination or harassment has also caused many to seek out other LGBTQIA+ individuals and their experiences online as their main source of LGBTQIA+ related health information and services [25, 22, 14]. Many use their fellow online community members to find LGBTQIA+ friendly and knowledgeable health information, experiences, providers, and services.

2.9 Conclusion

As designers, we may be able to provide optimized health information and care, facilitate the identification of possible health disparities, collect more precise data sets for stakeholders, create a more inclusive space for LGBTQIA+ individuals and normalize the collection of LGBTQIA+ identity information while producing a better understanding of this demographic by providing more options to select from and more identifiers to provide a more holistic picture and

base of health information. “The most salient challenge to meaningfully implementing sexual orientation and gender identity data collection in the EHR is developing data input algorithm signifiers that are clinically helpful to clinicians [8].”

Since the LGBTQIA+ demographic is an untapped data set to use, market, sell and disseminate, using a more robust demographics data collection method including LGBTQIA+ identity information may result in a more nuanced niche data set. However, the rare collection of LGBTQIA+ identity information implies missed opportunities of more in-depth analysis of the collected data. Hence, timely collection of LGBTQIA+ identity data can provide extremely useful information about the community and serve valuable insight to an under-studied population. Using demographic questions that identify LGBTQIA+ individuals like current sex, sex at birth, sexual orientation, gender identification, preferred name and pronouns may allow for the creation of more productive algorithms and in-depth data analysis to create better health information and services for the LGBTQIA+ population.

In next chapter, we explore the various resources LGBTQIA+ individuals use when seeking health information and services to understand if not collecting and using LGBTQIA+ identifiers impact their health information seeking. We also investigated if digital sources provide those who identify as LGBTQIA+ with reliable, accurate, and inclusive health information and services that cover all their needs as LGBTQIA+ individuals?

3 RESOURCES USED TO SEEK HEALTH INFORMATION

In this chapter, we explore the various resources LGBTQIA+ individuals use when seeking health information and services to understand how not collecting and using LGBTQIA+ identifiers impact their health information seeking. We attempted to determine in what ways different resources were used to approach LGBTQIA+ health information seeking than general health and why, in the hopes of illuminating any additional challenges and accessibility issues LGBTQIA+ individuals face when using various resources to seek health information and services. We also investigated how well digital sources provide those who identify as LGBTQIA+ with reliable, accurate, and inclusive health information and services and how well their health information needs are being met.

The study found both survey respondents and interviewees used a variety of strategies and resources to seek health information and those chosen changed depending on whether they were looking for general health or LGBTQIA+ health information. The Internet was a frequently used resource for seeking health information with several factors driving its use: its speed, convenience, ease of use, affordability, anonymity, comfortability, and minimization of possible discriminatory interactions. Multiple challenges were experienced by LGBTQIA+ individuals when using the Internet to find health information and services: accuracy and credibility determination, health literacy limitations, an overabundance of information, exaggeration of diagnoses, and a lack of peer reviewed LGBTQIA+ health information. Social media websites were the main source for LGBTQIA+ health information due to a lack of results from online searches. Voice assistants were infrequently used in relation to health due to a lack of desire to

or knowledge of how to, recognition issues, privacy concerns, and a preference to enter information in manually.

3.1 Methodology

Our study used a mixed methods approach. Anonymous surveys (n=155) and interviews (n=29) were asked both close-ended quantitative and open-ended qualitative questions to explore how LGBTQIA+ individuals currently navigate and seek health information. Affinity diagramming was used on the qualitative data and various types of statistical analysis was conducted on the quantitative data to identify shortcomings in LGBTQIA+ health information and additional challenges experienced when accessing it. Our study explored how LGBTQIA+ individuals navigate seeking health information and utilize different resources to seek general and LGBTQIA+ focused health information. We investigated if the LGBTQIA+ participants used different in person and online health information resources and strategies to seek general health information versus LGBTQIA+ health information while also noting any benefits or challenges encountered when using these sources. Our findings may provide insight into shortcomings in health information itself or technologies used to access the information, so that they may be addressed to create a more equitable and accessible health experience for the LGBTQIA+ community.

Additional findings from this research are presented in Chapter 4 and Chapter 5. The impact the COVID-19 pandemic had on the survey respondents' health information and services seeking and if their previous experience using digital health sources helped them navigate the pandemic is discussed in Chapter 4. In Chapter 5 if health care professionals are collecting and using gender identity, sexual orientations, pronouns, and other LGBTQIA+ related identifiers as

part of the health record as recommended by so many health institutions in the United States is investigated.

3.1.1 Participants

Both respondents and interviewees were recruited through direct emails and digital flyers posted on local, university, regional, and national LGBTQIA+ organizations', centers', clubs', and support groups' websites, social media platforms, and newsletters across the United States. This was not a truly random sample for either the survey or interviews, resulting in demographic differences between our sample and the US general population in terms of race, ethnicity, age, and education attainment level. The survey had 155 uncompensated respondents who were over the age of 18 and self-identified as a member of the LGBTQIA+ community. A total of 29 individuals were interviewed, all over the age of 18, whom self-identified as LGBTQIA+, and lived in the United States.

3.1.2 Data Collection

An uncompensated, anonymous online survey was conducted using Qualtrics Software between November 2020 and May 2021. Both qualitative and quantitative data were collected through 70 close-ended questions and 19 short, open-ended questions to elicit information about respondents demographics, LGBTQIA+ identity, health information seeking behaviors, health insurance access, and prescription drug access. Questions related to their mental health and primary care access in relation to the pandemic and technology use were also investigated. Not all questions were answered by each respondent; questions may have been skipped based on their earlier responses. There were 155 completed surveys using the question set found in C.1 Survey

Question Set. All survey related artifacts can be found in APPENDIX C: SURVEY STUDY ARTIFACTS.

Online virtual interviews were conducted using Zoom Software between Feb 2021 and Sep 2021 to acquire a better understanding of how LGBTQIA+ individuals' use technology to seek health information and services and interact with their health care professionals.

Interviewees were recruited through direct emails and digital flyers posted on local, university, regional, and national LGBTQIA+ organizations', centers', clubs', and support groups' websites, social media platforms and newsletters across the United States. A total of 29 individuals over the age of 18, whom self-identified as LGBTQIA+, and lived in the United States were interviewed. Almost all interviewees, 27, were compensated upon completion of the interview with a \$20 gift card for their participation. The first 2 participants were not compensated as funding had not been secured nor offered to them, they volunteered their time to participate. After securing generous funds from University of Michigan–Flint CAS Opportunity Fund, 25 participants were compensated with a \$20 gift card. The final 2 participants were also compensated with \$20 gift cards but those were paid for from the researcher's personal funds.

A semi-structured guide of qualitative questions that expanded on the survey questions were used to facilitate the interviews. LGBTQIA+ interviewees were asked broad, open-ended questions about how they sought health information and services, their interactions with their various healthcare providers, the health technologies they use, experiences with health insurance, barriers and discrimination experienced within the healthcare setting and if their health needs were being met. The interviews lengths ranged from 30 to 90 minutes, were audio and video recorded via Zoom. As with the surveys, not all questions were answered by each interviewee; questions may have been skipped based on earlier responses.

Survey data along with the Zoom produced transcripts, audio and video recordings for the interviews were downloaded and stored on an IRB approved secure University server. De-identification occurred via transcription and de-identified documents were stored separately from identifiable ones on the same secure server. The interview question set can be found in B.2 Interview Question Set.

3.1.3 Data Analysis

Using a mixed-method approach we were able to collect a rich data set to analyze. We used the interviews to provide more in-depth findings than were captured with the surveys alone. Thematic analysis was done by performing affinity diagramming on the qualitative data. Affinity diagramming was used to analyze the narrative data to identify emerging themes. Descriptive statistics and inferential statistics were used to analyze the quantitative data. Bivariate analysis was then conducted between the general population and our LGBTQIA+ participants. Much of the survey data was analyzed prior to conducting interviews to better formulate the interview question set.

3.2 Participants' Demographics

The participants, from neither the interviewees nor the survey respondents, were representative of the US population with respect to age, race, ethnicity, and education level. Our study's cohort was very young and well-educated, this skew is likely due to the use of digital media for recruitment and to conduct the survey.

Table 3-1: Age, Race, Ethnicity and Marital Status

	Interviewees (29)	Survey Respondents (155)	U.S. General Population [26]
18-25	41.4%	34.5%	--
26-35	34.5%	27.9%	13.9%

36-45	13.8%	14.5%	12.8%
46-55	3.4%	5.5%	12.4%
56-65	3.4%	6.7%	12.9%
66-75	3.4%	8.5%	9.6%
76-85	0.0%	2.4%	4.9%
Over 86	0.0%	0.0%	1.9%

Race/Ethnicity

	Interviewees (29)	Survey Respondents (155)	U.S. General Population [26]
White / European American	37.9%	74.5%	60.0%
African American / Black	37.9%	8.5%	14.2%
Alaska Native / American Indian	3.4%	0.6%	1.7%
Asian / Asian American	6.9%	9.7%	6.8%
Biracial / Multiracial	3.4%	3.6%	3.4%
Latino / Hispanic	3.4%	8.5%	18.4%
Middle Eastern / North African	0.0%	3.0%	--
Native Hawaiian / Pacific Islander	0.0%	1.2%	0.2%
Jewish	6.9%	0.6%	--
Other	0.0%	1.2%	--

Relationship Status of

	Interviewees (29)	Survey Respondents (155)	U.S. General Population [27]
Married	17.2%	24.2%	47.6%
Registered domestic partnership	0.0%	2.5%	--
Widow	0.0%	2.5%	5.7%
Divorced	6.9%	8.9%	10.9%
Separated	0.0%	0.6%	1.8%
Single (all even in relationship)	72.4%	61.1%	33.9%
Unknown	3.4%	0.0%	--

Table 3-1 shows the interviewees' demographics: age, race, ethnicity, and marital status compared to the general population of the United States. Over 75% of interviewees and 62% of survey respondents were aged 35 and under. Again, this skew is likely due to the use of digital media for recruitment and to conduct the survey.

Table 3-2: LGBTQIA+, Gender Identity and Sexual Orientation Identification

Gender Identity and Sexual Orientation Identification					
Gender Identity	Interviewees (29)	Survey Respondents (155)	Sexual Orientations	Interviewees (29)	Survey Respondents (155)
Agender	0.0%	1.8%	Heterosexual / Straight	6.9%	6.0%
Bigender	0.0%	0.6%	Gay	37.9%	28.1%
Cisgender	58.6%	46.0%	Lesbian	10.3%	20.6%
Gender fluid	0.0%	0.6%	Bisexual	31.0%	33.6%
Gender non-conforming	0.0%	4.9%	Asexual	3.4%	5.5%
Gender normative	0.0%	3.7%	Pansexual	10.3%	16.4%
Gender queer	3.4%	3.1%	Demisexual	3.4%	6.9%
Nonbinary	3.4%	11.7%	Same-gender loving	0.0%	2.7%
Queer	6.9%	6.1%	Queer	10.3%	32.2%
Third gender	0.0%	0.0%	Other	3.4%	2.2%

Trans	27.6%	8.6%
Transgender	10.3%	9.8%
Transsexual	0.0%	1.2%
Two-spirited	0.0%	0.0%
Other	0.0%	1.8%

There was clearly a wide spectrum of gender identities and sexual orientations within the participants as the findings in Table 3-2 illustrate. The largest gender identity group from both cohorts were cis gender individuals, representing 46% of respondents and 58.6% of interviewees. Despite the difference in the participant count between the two groups, three times the number of interviewees (27.6%) identified as ‘trans’ than did respondents (8.6%) and those identifying as ‘transgender’ were almost equally represented between the two groups; 10.3% of interviewees and 9.8% of respondents.

Table 3-3 Pronouns of Participants

Pronouns	Interviewees (29)	Respondents (155)
she, her, hers	31.0%	42.0%
he, him, his	55.2%	36.9%
they, them	17.2%	14.0%
ze, zir	0.0%	0.0%
combination of pronouns (ze, they, she, and he)	13.8%	7.0%

Pronoun use also varied and was not consistent between the respondents and interviewees. The largest pronoun group of the interviewees was he, him, his with over 55% identifying as such, with only 36.9% of the respondents identifying as such. Considerably more respondents (42%) used she, her, hers than did interviewees (31%), making it the largest pronoun group within the survey cohort. Ze was used by a single respondent in combination with he, him, hir, hers. The rest who selected ‘other’ expressed their use of a combination of they and he or she.

Table 3-4: Education Level Attained & Employment Status

Education Level Attained & Employment Status			
Education Level	Interviewees (29)	Survey Respondents (155)	U.S. General Population [27]
Some high school, no diploma or GED	0.0%	0.6%	--
High school graduate or GED	6.9%	3.6%	26.7%
Trade / Technical / Vocational training work	0.0%	1.8%	--
Some college, no degree	13.8%	25.5%	20.3%
Associates degree	3.4%	4.8%	8.6%
Bachelor's degree	58.6%	29.1%	20.2%
Some graduate work, no graduate degree	0.0%	10.9%	5.4%
Master's degree (M.A., M.S., M.B.A)	6.9%	18.2%	--
Doctoral degree (Ph.D., Ed.D.)	6.9%	4.2%	--
Professional degree (M.D., J.D)	3.4%	1.2%	---
Graduate degrees (Masters, Doctoral and Professional)	17.2%	23.6%	12.7%

Employment Status			
	Interviewees (29)	Survey Respondents (155)	U.S. General Population [3]
Employed - Full time	48.3%	41.2%	--
Employed - Part time	17.2%	20.0%	--
Employed	--	--	60.20%
Self employed	6.9%	6.1%	--
Unemployed	24.1%	--	--
Unemployed - seeking employment	--	8.5%	--
Unemployed - not seeking employment	--	4.8%	--
Unemployed - due to disability	--	3.0%	--
Student	10.3%	24.8%	20%
Homemaker or caregiver	3.4%	1.2%	--
Work under the table	0.0%	1.8%	--
Illegal work	0.0%	1.2%	--
Retired	3.4%	8.5%	--
Other	0.0%	2.4%	--

Table 3-4 displays the education level and employment status of both the LGBTQIA+ identifying interviewees and survey respondents, and U.S. general population. The interviewees and survey respondents were highly educated, significantly higher than the general U.S. population's education level. Nearly 80% of interviewees and nearly 70% of the survey respondents had earned an associate degree or higher, far higher than the 45% of the general population who had done the same [23]. Nearly 76% of interviewees and 63.6% of survey respondents held a bachelor's degree or higher. 17% of interviewees and 23.6% of respondents held a graduate degree. In contrast, the U.S. Census Bureau found in 2020 that the general population's educational attainment was far lower: 35% held a bachelor's degree and 12.67% held a graduate degree [28].

Despite the higher level of education among the participants, the LGBTQIA+ individuals employment level was about the same as the general population of the United States; 65.5% for interviewees, 61.2% for respondents and 60.2% for the general population. This may illustrate some inequities in education to employment status for the LGBTQIA+ community.

Table 3-5 Health Insurance Coverage

Health Insurance Coverage			
	Interviewees (29)	Survey Respondents (155)	U.S. General Population
Insured	93%	92%	89.20%
Lost due to COVID-19	3.45%	3.40%	21%

Pre-pandemic, the LGBTQIA+ community had a higher percentage of individuals covered by health insurance, more than the general population, but were experiencing significantly more health disparities including transportation barriers, inaccessible prescriptions, inconvenient appointment times, reductions in health services, poorer perceived health status, and their mental health was more negatively impacted [29]. Our study found slightly more LGBTQIA+ survey respondents (92%) and interviewees (93%) had health insurance coverage than did the general population (89.2%) [30].

Employer sponsored health insurance plans covered 41.3% of interviewees. Nearly 25% of interviewees had purchased their own health insurance policy. Health insurance coverage provided by an attended university or through a spouse’s or parent’s health insurance plans were less commonly used sources. A state sponsored plan provided coverage for one interviewee and another qualified for Medicare. Only two, 6.9%, interviewees were uninsured. Of those two uninsured, one had a COVID-19 related job loss and, along with it, health insurance loss. The other uninsured interviewee used his friend’s insurance policy when they needed to work around their own lack of insurance.

3.3 Fears of and Experiences with Discrimination

Despite increased acceptance, inclusion, and representation of LGBTQIA+ individuals nowadays, only 58.9% of survey respondents considered themselves “fully out” in their personal and public lives’. Only 17% of interviewees considered themselves “fully out”, 14% were “out”, and another 14% considered themselves “mostly out”; this means less than half, only 45%, considered themselves mostly to fully out. Nearly, 26% of survey respondents were out to some but “closeted” to others, 11% were out to friends but closeted to family, 10% were out in their private life but closeted in their public or professional life, and 1.4% were fully in the closet. This speaks volumes to perceived acceptance within society, when so many LGBTQIA+ individuals are still not comfortable being “out” to everyone.

Table 3-6: Out Level of Participants

Out Level of Participants	
Survey Respondents' "Out" Level (selected option(s) from list)	
"Out" level	Survey Respondents
Fully out	57%
Out to friends, closeted to family	13%
Out in private life but in the closet professionally	10%
Out to some but closeted to others	27%
Fully in the closet	2%
Other	10%
Interviewees' "Out" level (open ended question)	
"Out" level	Interviewees
Out to Everyone	17%
Out	14%
Mostly Out	14%
Out Indirectly	7%
Out to a select few	45%
Closeted	3%

Some interviewees discussed how they were “indirectly out”. This group did not “flaunt” their identity but were “proud and happy” to tell anyone if they asked. For one interviewee knowing when to approach the topic was difficult, “I don't know when it's appropriate to talk about my orientation”, “since I'm not dating anybody” “it just doesn't come

up in conversation” (p20 – they/non-binary/pansexual, bisexual). Interviewees who were out to a few people mentioned feeling comfortable disclosing their LGBTQIA+ to only people they had carefully selected and trusted. An interviewee described the struggles of coming out, “the reason for not being very open to my friends and relatives and the society at large is because like fearing the stigmatization or the isolation that I could face (p5 – he/cis/gay)”.

A closeted interviewee discussed how they navigated their sexuality and acceptance within their broader community “*my friends, my family, and my coworkers, we all interact very well because my sexual orientation doesn't have to be part of my relationship with my friends and families (p7 – she/cis/lesbian)*”. Many LGBTQIA+ individuals still did not feel comfortable disclosing their full identity to everyone including their families, again this speak volumes when so many LGBTQIA+ individuals are not comfortable being “out” to even their loved ones.

The fear of being discriminated against was so strong for some interviewees they did not provide correct information, in relation to their LGBTQIA+ identity, when asked by healthcare providers because they “don’t want to be discriminated again (p7 – she/cis/lesbian)”, 14% did not disclose their LGBTQIA+ identity to healthcare providers even when asked due to their fear of discrimination. Others waited until they trusted the health provider to disclose their LGBTQIA+ identity, “*until I trust you it’s very hard for me to disclose it (p10 - he/cis/gay).*”

This fear was justified 72% of interviewees had been discriminated against by a healthcare provider because of their LGBTQIA+ identity. Many hesitated to identify with full certainty what felt like discriminatory experiences:

“Like the whole you're not on birth control, how are you so certain you're not pregnant and then you can just tell that the person receiving the information is not comfortable with the information you've just shared and then the room gets awkward and you're alone in a room with this person. and it's a four-by-four room so it's more been I guess those kinds of exchanges and interactions more than outward something that's been said or done if that makes sense (p29 – she/cis/lesbian).”

“I did speak to her about some of my relationships with women and her description specifically says LGBTQ friendly or a specialist or something like that and when I was talking about the issues that I had

going on at the time she kind of had this weird look like she was a little uncomfortable (p28 – she/cis/bisexual)."

"When I was younger, I didn't really have a choice as to what doctor I can go to so I just didn't talk about certain things." "Now, was it because I was gay, I don't know it was never said but I can't guarantee it wasn't but I can't guarantee that it was either okay (p25 - he/cis/gay)."

For others, health care providers were *"assuming that because someone presents in some way, this is what they are, this is what they want (p23 – she, they/still figuring it out/bisexual)."* The patient's health care was then shaped by these biases. Even when identities were disclosed, they were not always respected or used. An interviewee had their pronouns listed *"clearly in notes"* in their health record at their health provider's office and the staff still did not use the correct ones, *"they just didn't think it was important enough to get my pronouns right, which was it just didn't feel good (p20 – they/non-binary/pansexual, bisexual)."*

Others discussed the blatant discrimination they had experienced while trying to receive care in their small, religious hometown.

"I'm from a really small town and it's very like Christian based from the south and comments would be made the entire time I was in the office dropping the 'F' word and it was just 'butch' and carrying on. My hometown is very 1920, 1930s still so like the whole town is very discriminatory, but like even the doctors there it's hard to [get safe care] (p15 – he/transman/queer)."

Another interviewee felt *"you cannot force someone to stop being homophobic I don't think that is possible (p21 – he/trans/gay)."*, it was better to avoid these providers as training would not help. Another discussed how they expected to be treated differently because of their LGBTQIA+ identity; *"as a trans person it's basically like these are the things and, like the injustices and like violations that you have to deal with in order to be like get the care that other people would get and it, you know it sucks (p19 – she/trans/pansexual)."* Discrimination experiences and fears deeply impact relationships between LGBTQIA+ individuals and their healthcare providers.

3.4 Health Information Seeking Resources

LGBTQIA+ individuals used a variety of in person resources when seeking health information. Family, friends, and healthcare providers were consulted when seeking general health information. Health centers, facilities, and hospitals, especially those focused on LGBTQIA+ health, were viewed as places to access LGBTQIA+ health information.

Table 3-7 Sources of Health Information Used by Survey Respondents

Sources of Health Information Used by Survey Respondents		
	General Health Information	LGBTQIA+ Health Information
Healthcare provider, facility, or organization	86%	46%
Library	30%	23%
LGBTQIA+ center or organization	13%	61%
Family and friends	62%	36%
Internet	74%	75%
Other	1%	5%

3.4.1 Family and Friends

For many LGBTQIA+ individuals, families and friends provided an outlet to discuss health information with people who shared similar life experiences. Unsolicited advice from family was received sometimes, but for nearly 38% of interviewees and 63% of survey respondents family and friends were an outlet to discuss general health topics with. Discussing health information with family and friends allowed interviewees the ability to select the health information they felt was “*appropriate*” and worthy because they “*trusted*” the person. Many turned to people in their lives, especially those who shared similar experiences, to supplement health information they had found online or when an online search had been unsuccessful. Interviewees found this strategy to be quite “*satisfying*”. Some interviewees found it difficult to find people whom they could confide in because they feared their family and friends’ reactions to their LGBTQIA+ identity. “*How will I tell my friends? How will they take it? When I say I am gay, so I prefer online (p10 – he/cis/gay)*”.

Nearly twice as many survey respondents discussed general health topics with family and friends as did LGBTQIA+ health topics. Trusted friends were more frequently the confidants to discuss LGBTQIA+ health information with and family members were used to discuss more general and mental health issues, if they spoke about health issues at all with their family.

3.4.2 *Library*

Although “*not as convenient*” as online, the library was often used for “*clarification*” and additional “*explanations*”. The information found in the library was considered to be “*proven*” and interviewees had more “*trust*” in the books housed within. For the older trans individuals the library held a nostalgic quality as the first place they could get albeit very limited, “*not very helpful*”, and often “*sensationalized*” health information relating to being trans “*long before the Internet came along (p2 – she/trans/straight)*”.

3.4.3 *Healthcare Providers, Centers, and Hospitals*

A few interviewees sought information in person or online from the nearest health institution or clinic, usually one that specialized in LGBTQIA communities because they were “*open*” and “*supportive in treating patients*”, “*fair to me*”. One felt the “*gender clinic*” they used was a “*phenomenal place*” and “*provide any and every bit of care up to surgery*” that “*a transgender individual could need*” and noted “*they make recommendations*” to other knowledgeable providers (p1 – she/trans). Another interviewee had found “*a lot of that information from the sperm banks who are sending you information*” “*resource pages*”, “*chat*”, “*web board*”, and an “*online community of people who are going through the same thing and talking about that information (p9-she/cis/lesbian, queer)*.”

Table 3-8 Health Information Sought from Healthcare Provider or LGBTQIA+ Centers

General Health Information	LGBTQIA+ Health Information
----------------------------	-----------------------------

Healthcare provider, facility, or organization	86%	46%
LGBTQIA+ center or organization	13%	61%

Participants frequently went directly to their healthcare providers for general health information. Nearly 86% of respondents sought general health information from their healthcare provider while less than half sought LGBTQIA+ health information from those same providers. The same trend appeared with interviewees. Healthcare providers were consulted when interviewees were unable to get the “full info” or repetitive suggestions online and when it was something they considered “serious” or “unusual”. Yet interviewees were much less likely to seek out LGBTQIA+ related health information from those same providers.

Why weren’t LGBTQIA+ individuals seeking related health information from their healthcare providers despite over 82% of survey respondents having a primary care provider? Especially when most participants felt their primary care provider, and all felt their mental health professionals, treated them with respect. Most respondents were satisfied with the care they were receiving: 82% were satisfied with the care they received from their primary care provider and 92% were satisfied with the care they received from their mental health professionals. Beyond that our research found some huge differences in perceived care as it relates to a patients LGBTQIA+ identity that appear between primary care providers and mental health professionals that may help to explain this.

Respondents felt mental health professionals are not only much more likely to acknowledge their patient’s LGBTQIA+ identity, but they are also more sensitive to their health needs as a LGBTQIA+ individual, better at addressing those health needs and have the knowledge to provide LGBTQIA+ pertinent care. Less than 60% of respondents felt their primary care provider acknowledged their LGBTQIA+ identity.

Many interviewees stated that healthcare providers may be “LGBTQIA+ friendly” and/or respectful but that did not necessarily mean they were knowledgeable about or sensitive to their health issues as a LGBTQIA+ individual. Less than half (49%) felt their primary care provider was knowledgeable about their health needs as a LGBTQIA+ individual and 20% of respondents said their primary care provider had little to no knowledge about the LGBTQIA+ community or their health needs. *“I would have to educate them about what being trans is and where I fit within the spectrum of LGBT (p2).”* Nearly 20% of interviewees discussed the struggles and hassle of having to educate their primary care and other healthcare providers about their LGBTQIA+ identity and their health needs as a member.

Both respondents and interviewees reported that healthcare providers could be respectful of patient’s LGBTQIA+ identity and still provide subpar care through a lack of knowledge, sensitivity, and an inability to address LGBTQIA+ topics. LGBTQIA+ individuals may not seek out LGBTQIA+ health information from their healthcare provider because they feel they do not possess the knowledge to provide it not because they do not respect or acknowledge their LGBTQIA+ identity.

“It matters in a health professional yeah even if you're not talking specifically about LGBT related health issues it's still matters that the person who's becoming very intimate with your body respects your pronouns and your identities and all of that and understands how it could affect the way that you're feeling about the language that they use with you and things like that. ((p23 – she, they/still figuring it out/bisexual))”

Treat you with respect?					
	Very much	Somewhat	Neutral	Very little	Not at all
Primary Care Provider	73.5%	14.3%	10.2%	2.0%	0.0%
Mental Health Professional	83.9%	16.1%	0.0%	0.0%	0.0%

Acknowledge your LGBTQIA+ identity?					
	Very much	Somewhat	Neutral	Very little	Not at all
Primary Care Provider	49.0%	9.2%	23.5%	6.1%	12.2%
Mental Health Professional	59.7%	27.4%	8.1%	3.2%	1.6%

Address your medical needs as a LGBTQIA+ individual?

	Very much	Somewhat	Neutral	Very little	Not at all
Primary Care Provider	39.8%	16.3%	23.5%	8.2%	12.2%
Mental Health Professional	53.2%	17.7%	21.0%	4.8%	3.2%

Sensitive to your medical needs as a LGBTQIA+ individual?

	Very much	Somewhat	Neutral	Very little	Not at all
Primary Care Provider	43.9%	10.2%	28.6%	7.1%	10.2%
Mental Health Professional	51.6%	21.0%	17.7%	6.5%	3.2%

Knowledgeable about your medical needs as a LGBTQIA+ individual?

	Very much	Somewhat	Neutral	Very little	Not at all
Primary Care Provider	31.6%	17.4%	30.6%	11.2%	9.2%
Mental Health Professional	41.9%	24.2%	22.6%	9.7%	1.6%

Are you satisfied with the care you receive?

	Very much	Somewhat	Neutral	Very little	Not at all
Primary Care Provider	50.0%	31.6%	11.2%	5.1%	2.0%
Mental Health Professional	58.1%	33.9%	4.8%	3.2%	0.0%

Many participants sought various types of health providers online: mental health, LGBTQIA+ friendly, and primary care providers (see Table 3-9: Percent Who Sought Health Providers Online (LGBTQIA+ Survey Respondents)).

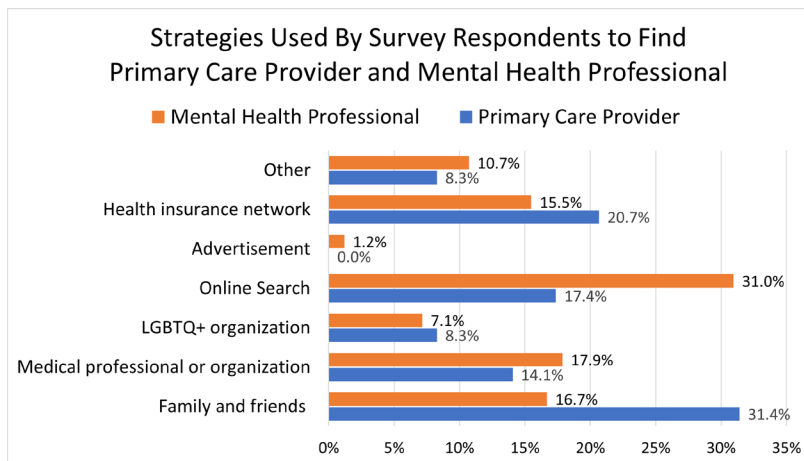
Table 3-9: Percent Who Sought Health Providers Online (LGBTQIA+ Survey Respondents)

Health Providers Sought Online	
Provider type	Percent
LGBTQIA+ friendly health providers	63%
Reproductive health providers	32%
Mental health providers	67%
Primary care providers	63%
Specialty medical providers	58%

Finding LGBTQIA+ knowledgeable healthcare providers is a challenge, even more so when health insurance networks were considered. The most frequently used resources to find LGBTQIA+ friendly healthcare providers were family and friends, health insurance networks, and online searches; see Figure 3-1 Strategies Used by Survey Respondents to Find Healthcare Providers. Despite the use of these sources, finding knowledgeable health care providers is a challenge.

For many participants the ability to find safe providers on the Internet was crucial as it was seen as a way to minimize the possibility of experiencing discrimination because it allowed them to safely research LGBTQIA+ friendly (and knowledgeable) healthcare providers prior to interacting with them. Yet despite this need there is no well-known, easily accessible nationwide database of LGBTQIA+ friendly and knowledgeable healthcare providers making the task extremely difficult and possibly a dangerous activity for the LGBTQIA+ community. Some feared their current healthcare provider would discover their LGBTQIA+ identity and discriminate against them, forcing them to seek other sources, often online, to fill in the gaps of LGBTQIA+ health information they were too afraid to ask their healthcare provider about.

Figure 3-1 Strategies Used by Survey Respondents to Find Healthcare Providers



3.4.4 Online Searches, a Main Source of General Health Information

Most participants in both groups used the Internet to seek health information; yet how and when the Internet was used varied according to interviewees. Nearly 14% of interviewees used the Internet as their main source of health information. For another 24% online was the first step to health information seeking while others used it as a second step in their health information seeking strategy, usually after speaking with a healthcare provider. One interviewee had moved

during the height of COVID restrictions, and because of this, the Internet had become their sole source of health information and care as they were unable to find a LGBTQIA+ friendly and knowledgeable health provider online to see in their new location. Some interviewees felt online could be “*misleading*”, “*unreliable*”, and incomplete. Due to its high use for finding health information Internet availability deeply impacted and shaped health information accessibility.

Half the interviewees said they had sought health information via a Google search. An ability to find “*everything*” and anything that “*popped into my mind (p17 – he/cis/gay)*” through a Google search was deeply appreciated by some interviewees. If the search results were irrelevant or unsatisfactory, interviewees would merely move onto the next result until they found the health information they were looking for. Misleading or paranoia inducing results were mentioned by almost 38% of interviewees, causing some not to use search engines to find health information. “*Danger of going down the rabbit hole and thinking that you're going to die from every symptom you have (p23 – she, they/still figuring it out/bisexual).*” Google searches for trans related health information resulted in “*very little quality imperial research (p22 – she/trans/straight)*” causing some to avoid its use for that topic and instead turn to social media for trans related health information from their peers.

Characteristics of Trusted Health Websites

Knowing what websites to trust was a major concern for LGBTQIA+ interviewees, with many restricting themselves to “*trusted medical institutions*” and government websites. A few discussed how the looks of website played into the site’s perceived credibility. Websites with “*less ad content*” and “*more professional*” looks were seen as more trustworthy. “*Religious leaning sites*” and “*yahoo searches*” were avoided. Only one interviewee discussed a very helpful specific LGBTQIA+ website that had helped them throughout their health and gender

identity journey, but for the most part interviewees performed new online searches for each new health topic they were seeking information on instead of revisiting a specific health website.

“*Popular and well-known (p26 – he/cis/gay)*” sites were often considered trusted sources from the search results; 20.7% of interviewees used WebMD and 6.9% used Mayo Clinic websites when seeking health information. Both sites were often considered to have reliable and accurate information to meet general health information needs, but many mentioned they lacked the LGBTQIA+ specific health information they were often seeking. The lack of and a desire for a WebMD or Mayo Clinic style website for LGBTQIA+ individuals was mentioned by several interviewees. Interviewees felt these sites were better organized and “*like healthcare providers are behind it (p28 – she/cis/bisexual)*” making them appear “*more credible*”. Despite many enjoying well-known sites some interviewees did not feel the same; just over 10% of interviewees avoided using WebMD. One interviewee had been told it received funding from pharmaceutical companies and to “*beware*” if it was “*strongly recommending (p20 – they/non-binary/pansexual, bisexual)*” certain drugs, another did not like how it returned scary diagnosis for simple symptoms. There was a mixture of feelings about using Wikipedia with a single respondent “*fairly*” trusting it, but most did not trust it as they recognized it could be altered by anyone.

Health Topics Sought Online

Many health topics were sought by respondents, some much more frequently than others. General health information had been sought by 84% of respondents (see Table 3-10), LGBTQIA+ related health information had been sought by 71% of respondents (see Table 3-11). Information about COVID-19 was a newly heavily researched topic. According to interviewees when topics were found it was related to the broad LGBTQIA+ group not the more nuanced,

subgroups making niche health information difficult to find. Respondents sought health information about the symptoms they experienced as well as the medicines they were prescribed and their side effects. Fitness, exercise, diet, nutrition as well as treatment information and the ability to self-diagnose were other commonly sought health topics, see Table 3-10 General Health Topics Sought by Survey Respondents.

Table 3-10 General Health Topics Sought by Survey Respondents

General Health Topics Sought Online	
Topic	Percent
General health information	84%
COVID-19	77%
Symptoms	76%
Fitness or exercise	69%
Information to self-diagnosis	66%
Diet or nutrition	63%
Treatments	62%
Procedures	50%
Diagnosis from healthcare provider	44%

Medicine Information Sought Online	
Topic	Percent
Prescribed medicines and side effects	79%
Over the counter medicines	58%
Home remedies or cures	53%
Medical devices or equipment	29%

Table 3-11 illustrates how many respondents sought LGBTQIA+ related health topics. Over 70% of survey respondents had researched LGBTQIA+ related health topics, nearly two-thirds had researched LGBTQIA+ friendly health providers online, almost half had researched sexuality or sexual attraction online and 42% had researched transitioning. Health insurance costs and coverage were researched by many respondents, as is shown in Table 3-12.

Table 3-11: LGBTQIA+ Health Information Sought Online by Survey Respondents

LGBTQIA+ Health Information Sought Online	
TOPIC SOUGHT	% Who Had
LGBTQIA+ related health information	71%
LGBTQIA+ friendly health providers	63%
Sexuality or sexual attraction	49%
Transitioning	42%

Table 3-12: Health Insurance Information Sought Online - LGBTQIA+ Survey Respondents

Health Insurance Information Sought Online	
Topic	Percent
Health insurance costs	50%
Health insurance coverage	61%

Over half of survey respondents had sought sexual health or family planning information. Just under half had sought health information about STIs. Table 3-13: Sexual Health Topics Sought Online, by Topic - LGBTQIA+ Survey Respondents displays the sexual health topics that were sought by respondents. Two-thirds of respondents had sought health information about depression, anxiety, suicide, and/or mental health professionals. Table 3-14 shows the frequency of some of the mental health topics researched online.

Table 3-13: Sexual Health Topics Sought Online, by Topic - LGBTQIA+ Survey Respondents

Sexual Health Topics Sought Online, by Topic	
Topic	%
Sexual health information	60%
Reproductive health providers	32%
Family planning	55%
Condoms, contraceptives, or other birth control	37%
Sexually transmitted diseases and infections	47%
Sexual assault	11%

Table 3-14: Mental Health Topics Sought Online - LGBTQIA+ Survey Respondents

Mental Health Topics Sought Online	
Topic	%
Mental health providers	67%
Information related to depression, suicide or anxiety	69%
Drug or alcohol abuse	21%
Domestic violence or abuse	22%

Perceived productivity and accuracy of Internet health information

The study investigated if health information needs were being met and the perceived productivity and accuracy of the resulting health information was also explored to determine if LGBTQIA+ individuals are able to find the health information and services they seek. The findings should provide insight into if there are shortcomings in health information or in the technologies used to access it so that they may be addressed.

Despite the frequent use of the Internet for health information, three times the respondents found it somewhat to very difficult to find LGBTQIA+ health information compared to those

who found general health difficult to find, 48% and 16% respectively. Nearly 80% of respondents thought that general health information was somewhat to very easy to find compared to 35% who felt the same about finding LGBTQIA+ focused health information. Once found general health information results were thought to be more accurate (78%) and more productive (83%) than LGBTQIA+ health information. Only 59% felt LGBTQIA+ health information was accurate and 65% felt it was productive when found.

Table 3-15: Difficulty, Productivity & Accuracy of General Health, LGBTQIA+ Focused Health and Mental Health Information Found Online

Difficulty, Productivity & Accuracy of General Health, LGBTQIA+ Focused Health and Mental Health Information Found Online						
Difficulty of Finding Health Information Online						
	very	somewhat	neutral	not very	not at all	have not searched
General Health Information	3%	11%	16%	37%	31%	2%
LGBTQIA+ focused health information	7%	35%	18%	15%	14%	11%
Mental Health Information	8%	20%	19%	25%	13%	15%
Productivity of Online Results for Health Information						
	very	somewhat	neutral	not very	not at all	have not searched
General Health Information	19%	49%	20%	7%	3%	2%
LGBTQIA+ focused health information	13%	44%	20%	14%	2%	8%
Mental Health Information	6%	40%	21%	18%	4%	12%
Accuracy of Online Results for Health Information						
	very	somewhat	neutral	not very	not at all	have not searched
General Health Information	15%	50%	24%	8%	1%	2%
LGBTQIA+ focused health information	8%	44%	27%	11%	2%	8%
Mental Health Information	5%	36%	27%	17%	3%	12%

Unmet Health Information Needs

General health information needs were met somewhat to fully for 82% of survey respondents, but only 54% felt the same way about their LGBTQIA+ specific health information needs and 61% about their mental health information needs. Specialized topics like sexual health, family planning specialty care and health insurance information needs went unmet for survey respondents, see Table 3-16 for more detailed information.

Table 3-16: Health Information Needs Met, by Area (LGBTQIA+ Survey Respondents)

Health Information Needs Met, by Area					
Type of Health Information	fully	somewhat	neutral	not quite	not at all
General Health	38%	44%	12%	5%	2%
LGBTQIA+ Specific Health	21%	33%	23%	17%	7%
Mental Health	21%	40%	18%	17%	3%

Sexual Health	26%	27%	32%	20%	4%
Family Planning	16%	13%	56%	9%	5%
Specialty Care	15%	33%	31%	15%	7%
Health Insurance	30%	26%	21%	15%	8%

Credible, research based LGBTQIA+ health information is hard to find, 42% of respondents said that it was somewhat to very difficult to find, compared to only 16% who said the same thing about general health and 31% who thought mental health was hard to find. Mental health was said to be the least productive category with 23% of respondents stating their health searches were not very to not at all productive. Mental health was also thought to have the most inaccurate results when searching health information. 24% of respondents thought the results were not very to not at all accurate, 15% felt that way about LGBTQIA+ and 10% about general information. Finding credible and accurate health information on a variety of topics is a challenge for LGBTQIA+ individuals.

3.4.5 Perceived Benefits of Social Media Websites for LGBTQIA+ Health Information

Digital social interactions were used as a main source of LGBTQIA+ health information. Nearly 28% of interviewees sought out other LGBTQIA+ individuals' personal experiences with health on social media websites because they found it an informative and satisfying source of information. Some interviewees, nearly 11%, felt other LGBTQIA+ individuals could understand and offer better guidance to the challenges and experiences they were facing. Social media and personal experiences gave some the feeling of not being alone and for other interviewees, it even helped them make sense of and define their own LGBTQIA+ identity.

Different social media groups were used to access information about corresponding health topics; breastfeeding questions were directed to “gay mother” groups, transitioning

questions to trans groups, and so on. Many LGBTQIA+ individuals felt they were able to get helpful responses from other LGBTQIA+ individuals with similar experiences quickly, even on the weekends. One interviewee discussed how help from social media groups allowed them to determine if they needed to seek emergency care or if what their child was experiencing was a common childhood illness that they were overreacting to as a first-time parent; through feedback from social media, they soon discovered it was the latter.

Many interviewees, especially trans, non-binary and those still determining their identity, were interested in hearing “*firsthand accounts*” and experiences from those living with similar identities. For a few interviewees, social media was the only place they could find health information from a LGBTQIA+ perspective. Nearly 37% of trans and transgender interviewees stated that social media websites were the only place they had been able to find trans related health information online. Social media websites were often used as a source to find LGBTQIA+ friendly and knowledgeable healthcare providers and facilities due to the availability of personal experience reviews allowing patients to avoid negative experiences with healthcare providers. Social media sites, like TikTok, were a main source of LGBTQIA+ health information and provided one interviewee and their trans spouse with much of their “*baseline information (p9 – she/cis/lesbian, queer)*” about transitioning. Trans health information was often sought out on established threads and through Reddit. Instead of searching online for LGBTQIA+ and trans specific health information, many interviewees sought health information directly from the Facebook groups they already belonged to.

For nearly 14% of interviewees firsthand experiences from the LGBTQIA+ community filled in areas of information that healthcare providers were not able to because they had not experienced it themselves firsthand, did not understand the nuances, or were just unaware.

Reading personal experiences was found to be helpful, but interviewees “*take them with a grain of salt (p2 – she/trans/straight)*” as they recognize they are anecdotal. Personal experience-based health information was preferred over research and data by nearly 7% of interviewees. One interviewee explained how personal experiences and interactions helped them to disseminate knowledge better and avoid the challenge of trying to determine the correct phrase to search for online on their own. “*If I’m asking someone else, I can just be like hey I don’t understand this part and they can try to figure out how to explain it in a different way (p22 – she/trans/straight).*” Asking others via social media alleviated interviewees from having to figure out what they needed to search, “*the burden of figuring out what I don’t understand is not on me, which really helps to cope with like a lot of frustrations that that comes with (p22 – she/trans/straight).*” Often, social media websites and groups led them to unexpected, nuanced, and more pertinent health information than they were unable to find when searching online alone.

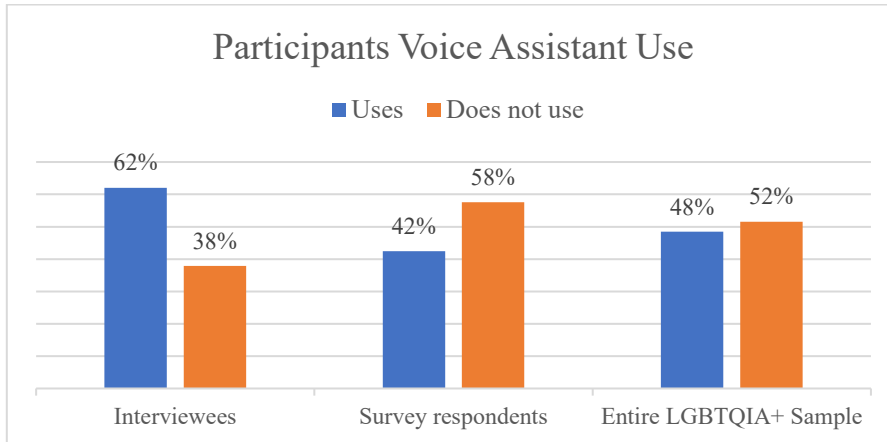
3.4.6 Voice Assistant Use for Health Information

For many the perceived inability to use and lack of knowledge about voice assistants dampened their use, especially for seeking health information. There were several concerns about surveillance, privacy, and misuse for some participants. Very few enjoyed verbally searching for health information via voice assistant technology due to the challenges experienced with inaccurate voice recognition; many found that using a voice assistant was more difficult and time consuming than entering the information by hand.

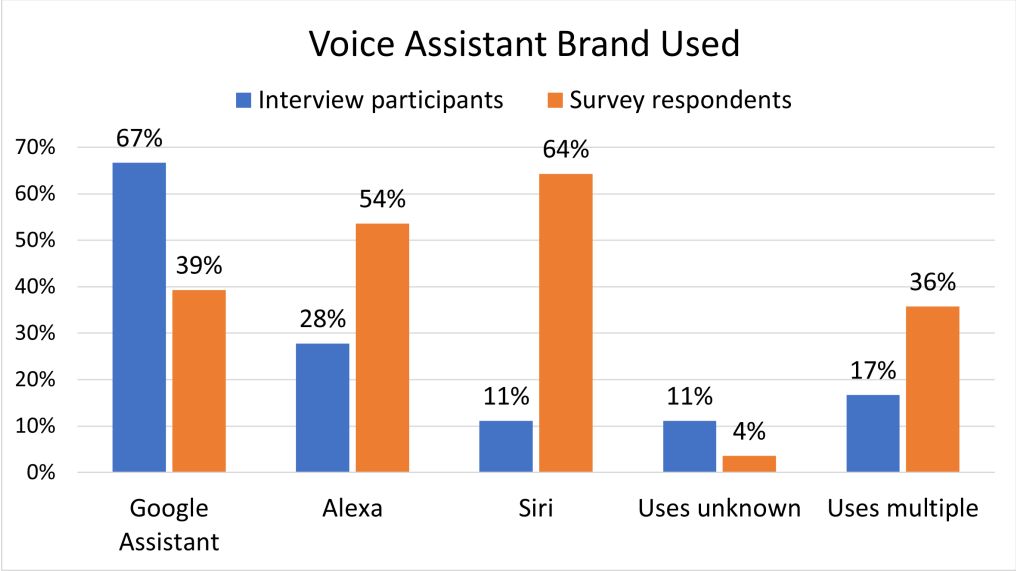
Voice assistant use varied significantly between interviewees and the respondent’s cohorts. Of the interviewees 62% used one or more voice assistant technology while significantly less, only 42% of survey respondents used a voice assistant. When the two groups were combined, and their usage averaged, it was a near 50/50 split of those who use voice assistant technology

and those who do not. Those using voice assistant technology used it for a variety of things, including health information seeking for some.

Table 3-17 Participants Voice Assistant Use



There was a drastic difference in which voice assistants were used between the interviewees and survey respondents. Over twice as many survey respondents (36%) used multiple voice assistants than did interviewees (17%). Interviewees heavily favored Google Assistant (67%) with it used two and half times more frequently than the next most used voice assistant, Alexa (28%) which was used two and half more frequently than the next Siri (11%). Nearly six times the amount of survey respondents used Siri (64%) than did interviewees (11%). Survey respondents used Siri most frequently but still 54% used Alexa, and 39% used Google Assistant; not the clear preference for one like the interviewees seemingly had.



Nearly 14% of interviewees did not use a voice assistant because they lacked information on how to use them. Others had no knowledge of what voice assistants were used for or capable of and had no idea they could be used in relation to health matters. Many respondents, 10%, never thought to use a voice assistant for their health needs. One respondent felt there was no reason to use them in anyway related to health. Some respondents believed trying to use it was “*too much (r133 – he/cis/gay)*” and would not be helpful.

Almost half the respondents lacked a desire to have a voice assistant, expressing a variety of reasons for why; many found them not useful (10%), were just uninterested (10%) or thought they were unneeded in their lives (30%). A third of interviewees experienced an assortment of functional issues including not maintaining engagement, interaction issues, and surveillance and privacy concerns.

There were several surveillance, privacy, and misuse concerns for participants. Nearly a third had issues with being surveilled all the time. A fear of “*Big Brother*” watching them kept 10% of the respondents from using voice assistants’ technology. Another 10% did not like the idea of being listened to all the time; others felt it was intrusive and even discomforting. A few

interviewees struggled to find a private enough space to safely use a voice assistant in and not be overheard for health-related use. Several interviewees had concerns about privacy and confidentiality, resulting in them not using a voice assistant for health-related tasks. The most vocalized worry for respondents, with nearly 17% mentioning it, was the chance of information misuse, by either a commercial or nefarious entity, which stopped many from using a voice assistant for health-related purposes.

Firsthand experiences with voice assistant technologies and their usability made individuals less likely to use them for health needs. Very few enjoyed verbally searching for health information via voice assistant technology. Due to the challenges experienced with inaccurate voice recognition, many found that using a voice assistant was more difficult and time consuming than entering it by hand; for many this problem was exacerbated when working with medical terminology. Others felt the nuance of the question was lost when a voice search was conducted, resulting in inaccurate results.

Some struggled to get the voice assistant to understand them, which caused weird searches which produced “*random*” results. One interviewee explained “*less of a problem with her and more of a problem with the English language and the multiple uses we have for words that she liked assumes you mean one thing because that's probably the most common usage and you mean a different one (p9 – she/cis/lesbian, queer)*” because of that “*she doesn't give you the right answer (p9 – she/cis/lesbian, queer)*.” One interviewee suggested an app to prevent misinterpretations by the voice assistant when searching information. The inaccuracy of the voice recognition slowed the health information seeking activity down for many who found it easier, faster, and more accurate to manually enter health information search terms into the device than to speak to them.

There was a mentioned preference to manually entering information by respondents (6.7%) and interviewees (13.8%) with several reasons given for this preference: ease, comfort, speed, and ability to manipulate. Many felt it was easier to input health information manually via the keyboard than through voice entry, often stating they were more comfortable with the keyboard. It should be noted, no one stated it was easier to find information of any kind via voice assistant than manual entry. The ability to manipulate a failed search query was thought to be easier if done manually when one was “*not getting the results (p2 – she/trans/straight)*”. Others stated that voice assistant searches resulted in different results than did manually inputted searches, not necessary less accurate but different results. Others felt the health information results produced were more reliable when inputted manually than when sought by voice assistant. The lack of comfort and familiarity with voice assistant searches lengthened the time they took to conduct, causing many to find searching manually faster and preferable.

3.5 Advantages to Internet Use

Many interviewees, over 17%, sought health information online because it was easy (20.7%), quick (13.8%), and convenient (10.8%). Online health information was considered “*cheap*” and thought to save money while over 17% noted it still costs substantially in time and effort. The same percentage of interviewees felt that online health information was “*accessible*”, “*readily available*”, and “*at your fingertips (p24 - all pronouns/genderqueer/pansexual, bisexual)*”. The ability to search any topic that came to mind when it came to mind was enjoyed by 14% of interviewees. Online searches provided relief, answers, and help to 31% of the interviewees, despite a realization they may not be “*really accurate*”. Online information was sought by nearly 14% of interviewees as a way to educate and inform themselves before or after interacting with a healthcare provider about a specific health topic.

Nearly 21% felt more comfortable searching health information online because it did not “judge” or ask about gender identity and sexual orientation when the searcher themselves may not know the answer to that question. The “anonymity” and “freedom” to search without “embarrassment” or judgement was mentioned by over 17% interviewees. Those with no one else to talk to or trust turned to the Internet for health information. Shame and trying to keep a “low profile (p8 – he/cis/bisexual)” about their LGBTQIA+ identity forced some to only seek certain health topics online. Nearly 7% had only sought LGBTQIA+ health information online, another 7% had only sought information online about their sexuality and almost 11% had only ever sought sexual health information online.

Internet use to find health information minimized the possibility of experiencing discrimination in several ways for over 17% of interviewees. Online searches allowed LGBTQIA+ individuals to safely research LGBTQIA+ friendly healthcare providers prior to interacting with them. Another fear was of their healthcare providers discovering and then discriminating against their LGBTQIA+ identity, forcing some interviewees to only seek LGBTQIA+ related health information online to minimize this risk.

3.6 Challenges of Using the Internet

Various challenges were experienced by many interviewees when seeking health information online. Determining accuracy and credibility was a challenge for many. Health literacy and knowledge of medical ‘jargon’ shaped, and in many cases limited, Internet results of health information. Knowing where to search was also an important component to accessing health information, as many considered health information to be scattered across the Internet with no centralized source. Escalating diagnoses from very simple symptom searches caused

panic for many. Too much health information and its unknown accuracy overburdened some, and for others searching for information was time consuming.

3.6.1 Health Literacy Shapes Results

Health literacy and ‘jargon’ knowledge was a major challenge experienced by nearly 21% of interviewees when seeking health information online. A “*game of semantics*” was how searching health information online was described, “*Google may answer part of the question, don’t know how to phrase to get to other part (p22 – she/trans/straight)*”. Another discussed why some verified health information sources may be avoided: “*People don’t have the language to understand what they’re reading, which is where some of the more verified sources can lose people. It’s jargon (p27 – he, they/ demigender/non-monosexual)*.” An example was shared by an interviewee of how they lacked knowledge about specialists and their specific professional specialty, “*I was like my nose was really stuffy for a while and I didn’t realize that there was like an eye nose and throat doctor and that that that there’s actually a term for that (p24 - all pronouns/genderqueer/pansexual, bisexual)*.”

Working in healthcare made finding research-based health information online easier, but those interviewees realized their ability was due to their professional training and that most others lacked that knowledge. All these experiences illustrate how online health information results are shaped by the searcher’s medical terminology and knowledge, often leaving those without medical background missing large amounts of information. It also shows the importance of online health information being easy to understand, especially for the layman.

3.6.2 Determining Accuracy & Credibility

Many LGBTQIA+ interviewees spoke of the large amount of health information available online. Some interviewees found online health information to be accurate. While nearly 28% of interviewees mentioned the inaccuracy of online health information. “60% of the time (p9 – she/cis/lesbian, queer)” online info is accurate, productive, and helpful. An interviewee explained that although online health information was “not accurate” “it is helpful” “it serves a purpose” “if I was curious about something I get to know more about it (p10 - he/cis/gay).” Several strategies were used by interviewees to determine the credibility and accuracy of health information found online, a very important step to interviewees when seeking health information.

To verify credibility and accuracy nearly 21% of interviewees, cross-referenced information found from one search result or social media post with information found on another. Similar health information found across sites allowed the information, and the providing website, to be deemed credible and accurate; if the health information did not match further investigation was done to determine which was the accurate one. Another strategy was using only specific websites or institutions deemed credible, like WebMD, national health organizations, and websites ending in .edu.

Others verified the health information online with a secondary source: a healthcare provider, a friend, or additional research at the library. Nearly a third of interviewees checked the accuracy or got clarification of online health information from their healthcare providers. Monthly meetings with a healthcare provider to verify health information was not enough for one interviewee, who wished they could meet biweekly to truly satisfy their health information needs. Concerns of credibility also involved “negative hate groups” who “make themselves seem so friendly” to those seeking LGBTQIA+ health information and support only to trick “gullible” people into conversion therapy (p1 – she/trans).

3.6.3 Credible LGBTQIA+ Health Information is Lacking

There was a preference for peer-reviewed health information but an inability to access it. Due to some interviewees' roles as a healthcare providers or educators at universities, they were able to find peer reviewed articles and had access to "*things that should be open access to the public that aren't (p9 – she/cis/lesbian, queer)*". Google Scholar was a preferred source, due to the accessibility of peer reviewed articles, for one interviewee. Universities, hospitals, and LGBTQ health centers, "*institutions and facilities that you can't question (p1 – she/trans)*" were used by some interviewees to access small amounts of research based LGBTQIA+ health information.

The lack of "research-based" LGBTQIA+ health information on the Internet was discussed by many interviewees. The inability to easily find research based LGBTQIA+ health information, like most could general health information, gave the appearance that research had never been conducted or had been so rarely studied it made it difficult to find. Some sought personal experiences from other LGBTQIA+ individuals in lieu of the missing peer-reviewed research because they themselves lacked the knowledge to search adequately online.

Those who were able to find peer-reviewed health information online often spoke of having an additional level of ability to do so due to work, as did the interviewees who had been searching for health information online for years; allowing them to know where to look for LGBTQIA+ peer reviewed health information. Both groups knew others would lack that same skill set and would not be able to find research-based health information, which was a common complaint from interviewees.

3.6.4 Too Much Information, Too Little Detail and Time to Find it

There were many challenges experienced when using the Internet to find health information. Some interviewees spoke of finding health information that lacked detail or was a topic close to what they were looking for but not exactly correct, making it inaccurate and unhelpful. Too much information, not all of it reliable, was an issue making it harder to decide what was relevant and needed information for some interviewees. Time constraints often impacted accessibility of quality health information. To find and access reliable, accurate, and pertinent health information online was time consuming and required a lot of work because it was “*not outright there (p7 – she/cis/lesbian)*”.

Escalating Diagnoses

Another challenge of using the Internet to find health information was the escalating severity of diagnoses in the results from minor symptoms entered, experienced by 17% of the interviewees. The vast amount of information available online made the issue worse for some, “*I think the issue might be that the Internet has too much so, if I have an issue and I go to the Internet well now, I feel like I have cancer and diabetes and schizophrenia, and all that, because you know symptoms are so similar across the board (p28 – she/cis/bisexual)*.” Another example was shared by a interviewee who had searched a simple cough and the results returned involved a deadly virus, “*results are generally quite alarming*” “*hard to not let your head kind of go there (p24 - all pronouns/genderqueer/pansexual, bisexual)*”. Some did not seek health information online to avoid the “*danger of going down the rabbit hole and thinking that you're going to die from every symptom you have (p23 – she, they/still figuring it out/bisexual)*” and the “*anxious moments (p27 – he, they/ demigender/non-monosexual)*” that followed.

3.6.5 Difficulty Finding LGBTQIA+ Health Information

Despite research showing increased prevalence of specific STIs or reproductive issues and mental health issues [8, 15, 23, 21, 24, 14] within the LGBTQIA+ community, finding LGBTQIA+ focused sexual and mental health was substantially more difficult for survey respondents than finding general health related information, with or without a LGBTQIA+ focus, as is shown in Table 3-18 Difficulty of Finding Health Information for Survey Respondents and Table 3-19: Difficulty of Finding LGBTQIA+ Focused Health Information Compared to General Health Information (LGBTQIA+ Survey Respondents)

Table 3-18 Difficulty of Finding Health Information for Survey Respondents

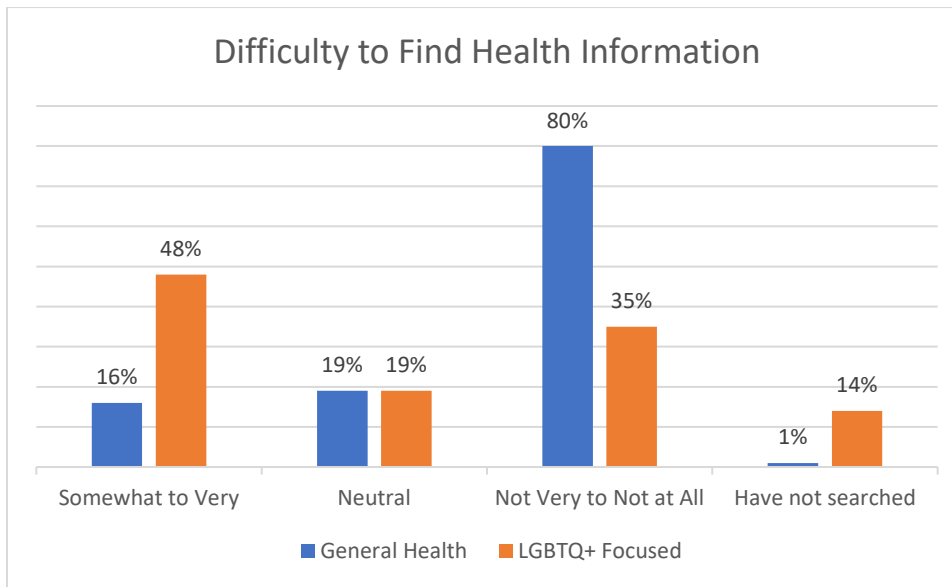


Table 3-19: Difficulty of Finding LGBTQIA+ Focused Health Information Compared to General Health Information (LGBTQIA+ Survey Respondents)

Difficulty of Finding LGBTQIA+ Focused Health Information						
	very	somewhat	neutral	not very	not at all	have not searched
LGBTQIA+ Focused General Health Information	7%	30%	15%	14%	13%	11%
General Health Information	3%	9%	15%	32%	29%	1%
LGBTQIA+ Focused Sexual Health Information	8%	21%	17%	21%	11%	14%
Sexual Health Information	2%	16%	15%	34%	20%	14%
LGBTQIA+ Focused Mental Health Information	20%	35%	12%	11%	5%	17%
Mental Health Information	8%	20%	19%	25%	13%	15%

Credible, research based LGBTQIA+ health information is hard to find, 48% of respondents said that it was somewhat to very difficult to find, compared to only 16% who said the same thing about general health and 31% who thought mental health was hard to find. Mental health was said to be the least productive category, with 23% of respondents stating their health searches were not very to not at all productive. Mental health was also thought to have the most inaccurate results when searching health information; 24% of respondents thought the results were not very to not at all accurate, 15% felt that way about LGBTQIA+ and 10% about general information.

3.6.1 Perceived Challenges of Using Social Media Websites for Health Information

Several challenges to using social media for health information were experienced by many interviewees. The unknown validity of the health information found on social media sites was a concern for several interviewees. Another concern was “*elders*” from the trans community with a substantial knowledge base of the entire transitioning process often stopped using social media sites a few years after transitioning; their knowledge was then lost. One interviewee suggested compensating elders through grants for the time they spend sharing their health experiences and knowledge on social media to ensure they continued to do so post transition. For one interviewee Facebook groups were avoided because they felt too many members of the groups were discouraging to LGBTQIA+ individuals.

The organization of social media data can make accessing and sharing the health information found on it difficult. Difficulties getting posts to show up in chronological order and search functions to work correctly were often experienced when trying to access health information from social media sites. Another issue encountered was the difficulty of sharing health information once found, especially with those who did not belong to the site or have access to the Internet. Archived and deleted posts or accounts created another problem when

trying to access previously found health information. These seemingly minor design issues, within social media sites, further impeded the already difficult task of searching for health information for the LGBTQIA+ community.

3.7 Disparities Experienced While Seeking Health Information and Services

Several disparities were experienced by LGBTQIA+ participants involved in the research study. Despite a larger percentage of respondents having health insurance coverage, less of our respondents felt like they were in good health than did the general United states population. Health insurance did not cover all their LGBTQIA+ health needs, leaving many to pay out of pocket or forego treatment. Finally, there were far more transportation barriers experienced by the survey respondents than the general population.

3.7.1 All LGBTQIA+ Health Needs are NOT Covered by Insurance

Having all of one's LGBTQIA+ health needs covered by insurance was experienced by 31%, nearly all covered by 14% and another 14% had most of their LGBTQIA+ health needs covered by insurance. Interviewees explained a variety of other reasons that increased the cost of basic care for LGBTQIA+ individuals. Several felt their insurance would not cover the costs of transitioning, two knew for sure it would not. One described how they had "*battled to get everything covered*" but insurance "*had an excuse for everything. It's cosmetic. It's not necessary (p1 – she/trans).*" Luckily, the interviewee had the ability to pay out of pocket for the care that was denied "*I don't regret any of it...for me everything worked out exactly the way it needed to (p1 – she/trans).*"

Table 3-20; Survey Respondents Health Needs Covered by Health Insurance

Survey Respondents Health Needs Covered by Health Insurance			
	Yes	No	Unsure/ Not Applicable
Referrals to specialists required	47.41%	25.00%	27.59%
Pre-existing conditions covered	57.76%	2.59%	39.66%
LGBTQIA+ related considered pre-existing	10.34%	17.24%	72.41%
PREP covered	24.14%	14.66%	61.21%
LGBTQIA+ needs covered	24.14%	8.62%	67.24%
Prescription coverage	83.62%	2.59%	13.79%
Mental health coverage	73.28%	9.48%	17.24%

Coverage of the expensive antiretroviral (ARV) drug PREP, used to prevent the transmission of HIV, was another issue of concern. One interviewee discussed how they were unsure if the prescription would be covered. Another interviewee knew PREP was not covered and had forgone taking the drug due to its cost without insurance coverage. Over 60% of survey respondents were either unsure of coverage or said it did not apply. The lack of or subpar coverage, and additional costs of family planning for LGBTQIA+ individuals was mentioned by a few interviewees. The fear of having a bad interaction with a healthcare provider was so strong that one interviewee who had lost their employer sponsored insurance felt it was necessary to pay out of pocket to continue to see their healthcare providers who they knew were trans friendly, experienced, and knowledgeable despite having free state provided health insurance that did not provide coverage to see these same providers.

3.7.2 Transportation Challenges

The main forms of transportation used by the LGBTQIA+ interviewees and survey respondents varied and differed considerably from the general population’s main forms reported by the Bureau of Transportation Statistics as shown in Table 3-21 [31]. Sixty percent of the LGBTQIA+ survey respondents and 55.2% of the LGBTQIA+ interviewees owned their own

vehicle, both considerably less than the 85% of the general population in the U.S. who owns a vehicle [31].

Table 3-21: Main Forms of Transportation

Transportation Type	LGBTQIA+ Interviewees	LGBTQIA+ Survey Respondent	U.S. General Population [31]
Own vehicle	55.2%	60%	84.8%
Public transportation	48.3%	12.7 %	5%
Subway	10.3%	9.1%	--
Public buses	31%	3.6%	--
Family & Friends	0	9.7%	--
Walking	6.9%	12.7%	2.6%
Car hire service	10.3%	3%	0.2%

Over twice the number of LGBTQIA+ survey respondents and nearly 10 times as many LGBTQIA+ interviewees relied on public transportation than did the general population of the United States: 9.1% of our survey respondents and 13.8% of interviewees relied on the subway, while 2.4% of survey respondents and 31% of interviewees relied on public buses. Another 12.7% of survey respondents and 6.9% interviewees walked, 8.5% of survey respondents relied on rides from family and friends, and 3% of survey respondents and 10.3% of interviewees relied on car hires (e.g., Uber) for their main form of transportation. COVID-19 impacted the type of transportation used; an increase in car hires was mentioned by a few interviewees as a way to mitigate the risk of exposure associated with mass public transportation during the pandemic.

3.8 Conclusion

Interviewees used a variety of resources to seek health information and services; the resource selected depended on the health information being sought. General health information was sought through online searches and through social interactions with healthcare providers, family, and friends. LGBTQIA+ health information was sought at libraries, health centers, and hospitals, but mainly, it was sought out through digital interactions on social media. Online searches were used to find general health information and social media was used to find

LGBTQIA+ health information. Online use for health information was driven by several factors: speed, ease of use, convenience, anonymity, freedom, comfortability, and minimization of possible experiences with discrimination.

Several challenges were experienced when using the Internet to seek health information: determining accuracy and credibility, health literacy, too much information – too little detail, escalating diagnoses from simple symptom inputs, the lack of peer reviewed “research-based” health information and the inability to find LGBTQIA health information and knowledgeable providers. In the next chapter, Chapter 4, the COVID-19 pandemics’ impact on how LGBTQIA+ individuals use technology to find health information, seek health services, and interact with their medical care professionals is investigated.

4 COVID-19'S IMPACT ON HEALTH INFORMATION SEEKING AND SERVICES

Discrimination and stigma fears lead many LGBTQIA+ individuals to seek out health information and services online and through other digital sources despite the design of these avenues not being inclusive of the community [25]. Has the LGBTQIA+ community's heavy reliance on digital use prior to COVID-19 lessen the impact they have experienced? Did the LGBTQIA+ community handle health-related platform transitions and the increased reliance on digital technologies for healthcare better than the general population or were the already documented disparities exacerbated? Could new technologies or improvements to existing ones improve not only LGBTQIA+ individuals' health information seeking experiences and access to health services, but also facilitate the provider-patient relationship?

This chapter investigates the COVID-19 pandemics' impact on how LGBTQIA+ individuals use technology to find health information, seek health services, and interact with their medical care professionals. Online surveys were conducted with 155 people who self-identified as LGBTQIA+ to acquire a better understanding of their health information seeking behaviors, their interactions with healthcare providers, and the technologies they used to manage their health and well-being, and how these might have been impacted by the recent COVID-19 pandemic. The goal was to identify possible challenges and barriers LGBTQIA+ individuals experienced during the COVID-19 pandemic when seeking health information and accessing health care services. How these challenges may be alleviated through new or improved technological solutions were also discussed.

In this chapter the impact of the COVID-19 pandemic on our LGBTQIA+ survey respondents technology use to seek health information, interact with their health care professionals, and find and access health services is explored. Detailed demographic information about the survey respondents discussed in this chapter can be found in Chapter 3.2 and in Table

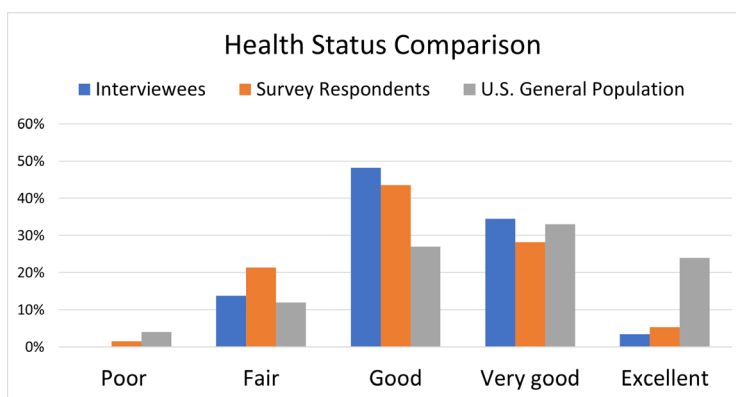
3-1: Age, Race, Ethnicity and Marital Status, Table 3-2: LGBTQIA+, Gender Identity and Sexual Orientation Identification, Table 3-3 Pronouns of Participants, Table 3-4: Education Level Attained & Employment Status and Table 3-5 Health Insurance Coverage. See Chapter 3.1 Methodology for detailed information about the methodology used in this research study.

4.1 Perceived Health Comparisons

4.1.1 Physical Health

The findings, shown in Table 4-2, indicated that nearly 78% of the LGBTQIA+ survey respondents felt they were in good to excellent health, lower than 84% of the U.S. general population who reported the same perception to the Peterson-KFF Health System Tracker [32]. The interviewees who considered themselves in good to excellent health aligned more with the general population at 85%. Only 5.8% of survey respondents and 3% of interviewees felt they were in excellent health, significantly lower than the 24% of the general population who felt the same, especially considering amongst the LGBTQIA+ participants there was a higher percentage of individuals covered by health insurance than the general population [32].

Table 4-1 Health Status Comparison



Nearly 21% of our respondents considered themselves to be in fair health, 50% higher than our LGBTQIA+ interviewees reported to us and nearly double the general population (12%) who

reported they felt the same to the Peterson-KFF Health System Tracker [32]. Notably, 4% of the general population felt they were in poor health, substantially more than the 1.65% of LGBTQIA+ survey respondents who felt that way in our study. The Peterson-KFF Health System Tracker found the general population were more likely to perceive their health status as excellent, very good and poor, placing more of the general population’s perceived health status at either ends of the spectrum of health [32]. Our research found LGBTQIA+ individuals are more likely to perceive their health status as fair or good, placing their perceived health status in the middle of the health spectrum despite a higher percentage having insurance coverage.

Table 4-2: Self-Assessed Health

Self-Assessed Health	LGBTQIA+ Interviewees	LGBTQIA+ Survey Respondents	U.S. General Population [32]
Poor Health	0%	1.65%	4%
Fair Health	14%	21%	12%
Good Health	48%	44%	27%
Very Good Health	34%	28%	33%
Excellent Health	3%	6%	24%

4.1.2 Mental health

According to the PRNewswire survey in April 2020, 75% of the general population in the U.S. reported that the COVID-19 pandemic had negatively impacted their mental health [33]. The mental health of 87% of the LGBTQIA+ respondents we surveyed had been negatively impacted by COVID-19. While the American Psychiatric Association reported 36% of the general population had faced issues with their mental health [34], our study showed that over 40% of our LGBTQIA+ respondents had experienced a great deal of mental health challenges due to COVID-19. Forty percent of our survey respondents had sought out mental health services to cope with the impact caused by the pandemic. For ten percent of the LGBTQIA+ respondents

who sought mental health services, it was their first time seeking mental health assistance. Several respondents indicated that their mental health issues had gotten so bad they greatly interfered with their daily lives, "*I am lucky to get anything done these days. Depression has really been holding me back (r115 – they/transmasculine, non-binary/asexual)*".

Three main themes emerged from Costa et al on the suggested ways to help the mental wellbeing of the general population during the COVID-19 pandemic: 1) the accessibility to mental health care, 2) self-care strategies, and 3) the continued need for community support and relationships [35]. Some of these same themes emerged within our surveyed LGBTQIA+ community as well.

4.2 Health Information Seeking

4.2.1 Strategies Used

COVID-19 impacted health information seeking strategies and accessibility for 27% of our LGBTQIA+ survey respondents. Due to decreased in-person access to medical providers, libraries, community, and health centers or organizations, some participants had to change the way they sought health information to becoming more heavily reliant on the Internet. In fact, some respondents resorted to solely seeking health information on the Internet, "*Just internet research. No longer going to or contacting doctors, libraries or other in person services (r58 – she/cis/bisexual, queer)*". In contrast, other respondents have become more reliant on family and friends for health information which was not the case before the pandemic, "*I have discussed medical conditions with friends that I did not discuss such matters before Covid-19 (r99 – he/queer/gay)*". Unfortunately, a small number of participants found the health information they needed inaccessible due to the constraints rendered by the pandemic.

4.2.2 Information Sought

The pandemic impacted not only the ways information was sought by LGBTQIA+ respondents but also the types of information sought. General COVID-19 information was the third most searched topic by our LGBTQIA+ respondents, just behind general health information and prescription drug information. A few LGBTQIA+ respondents mentioned specifically increasing their research on how to stay safe from the COVID-19 virus itself. A few others mentioned the addition of researching in-person appointment safety procedures and protocols instated due to COVID-19, *“I have had to read extensively online about the procedures necessary to set up appointments for my place of testing due to covid which really limited availability for appointments (r149 – he/cis/gay)”*. A few of those researching COVID-19 expressed the need for more credible information sources such as official health sites, *“I have been observing more official health sites and offices for information (r154 – she/non-binary/bisexual, queer)”*.

4.3 Health Care Accessibility

4.3.1 Transportation

Transportation has often been cited as a barrier to health care access which undoubtedly was further complicated by the pandemic. A few respondents indicated that they no longer used public transportation or ride shares while others expressed an increased reliance on walking, roommates, and Uber; *“Non-pandemic-NJ transit and subway; pandemic-Walking and uber (because I'm in NJ and not commuting to NYC) (r111 – they/agender/bisexual)”*.

4.3.2 Health Insurance

Slightly more LGBTQIA+ respondents had health insurance coverage (92%) than did the general population (89.2%) [30]. Table 4-3 illustrates the COVID-19 pandemic’s impact on health insurance coverage of our LGBTQIA+ respondents compared to the general population of the U.S. Pre-pandemic, the LGBTQIA+ community had a higher percentage of individuals covered by health insurance, more than the general population, but were experiencing significantly more health disparities including transportation barriers, inaccessible prescriptions, inconvenient appointment times, reductions in health services, poorer perceived health status and their mental health was more negatively impacted [29] and the pandemic only exacerbated those disparities. Nearly 21% of the general population had lost their employer-sponsored insurance due to COVID-19 [36], while only 3.4% of the LGBTQIA+ respondents had, significantly less than the general population. It appears that COVID-19 had a lesser impact on health insurance coverage for our LGBTQIA+ respondents than the general population. This may be due to the higher education level of our respondents, thus possibly providing the LGBTQIA+ group with higher job security.

Table 4-3: COVID-19 Pandemic’s Impact on Health Insurance

COVID-19 Pandemic’s Impact on Health Insurance		
Health Insurance	General	LGBTQIA+ Survey Respondents
Insured	89.2%	92%
Lost due to COVID-19	21%	3.4%

Fourteen percent of LGBTQIA+ respondents surveyed stated their insurance plans had changed, premiums had increased, and for some there was a reduction in overall coverage. Others were pleased that COVID-19 related expenses were covered by insurance and COVID-19 testing was free. Some discussed how their insurance began covering telehealth and virtual

medical appointments for the first time due to COVID-19, with some insurance companies even waiving copays for virtual appointments to encourage their use during the critical period of the pandemic.

4.3.3 Prescriptions

The LGBTQIA+ community experienced a disproportionately higher rate of inaccessibility to prescriptions due to the pandemic, significantly more so than the general population and is shown in Table 4-4. Some respondents had difficulties getting prescriptions after losing their health insurance:

“The challenge was once I lost my health insurance, during the pandemic was horrible, and I contacted my local health center after the state opened up and they help me with a prescription patient assistance program, and I got approved or allowed to continue receiving my medication. It was a long process but worth it now that I don’t have health insurance just lucky that I had resources within my own community (r137 – he/cis/gay).”

Nearly a quarter of the LGBTQIA+ respondents had to change how they received their prescriptions due to COVID-19. Of those who changed methods to obtain their prescriptions, three-quarters began to have them delivered via U.S. Postal mail to minimize their risk of exposure to COVID-19 virus. Some LGBTQIA+ individuals had experienced lengthy fights with their insurance companies to get their mail ordered prescriptions covered, sometimes weeks after receiving them.

“I tried to get mail order 90-day supplies for several of my transition-related prescriptions. Initially request was denied, and insurance claimed they needed more info and authorization from my provider, had to go back and forth with them several times and took several weeks to get order to go through. More recently, I

was informed via mail that some of my prescriptions were denied - not eligible for mail order apparently. They could've told me that weeks ago (r102 – they/non-binary/asexual, pansexual, demisexual, queer).”

A small number of LGBTQIA+ respondents no longer entered the pharmacy to pick up their prescriptions; instead, they took advantage of the pharmacy’s drive-thru or curbside pickup options to minimize their chances of exposure to COVID-19. However, the reduced hours of operation of pharmacies during the pandemic increased the difficulty and required better coordination with rides or family members in order to secure their prescriptions. In addition, a few respondents had to switch pharmacies because their previous pharmacy had been near their place of employment, but they had switched to working from home virtually or were no longer employed there.

Table 4-4: COVID-19 Pandemic’s Impact on Health Care, Mental Health and Medication

COVID-19 Pandemic’s Impact on Health Care, Mental Health and Medication		
Health Care	General	LGBTQIA+
Appointments canceled or postponed due to COVID-19	12.7% [34]	23%
Not seen a doctor due to cost in past 12 months	13.4% [35]	20%
Experienced a platform change for appointments	--	58%
Satisfied with platform change	83% [33]	70%
Mental Health Care		
COVID-19 pandemic negatively impacted mental health	75% [28]	87%
Had a serious impact on mental health	36% [29]	41.50%
Experienced a platform change for appointments	50% [36]	90%
Satisfied with platform change	--	75%
Prescription Medications		
Changed how they received their prescription medication(s)	--	23%
Had difficulty accessing their prescribed medications	3% [28]	18%
Health Insurance		
Insured	89.2% [33]	92.50%
Lost insurance due to COVID-19 pandemic	21% [34]	3.40%

Over 18% of our LGBTQIA+ respondents had difficulties getting their prescriptions due to COVID-19, this was substantially higher than the 3% among the general population according to the National Center for Health Statistics [37]. Of the LGBTQIA+ respondents who had difficulties accessing prescription, 55% were individuals whose gender identity had changed over their lifetime and 35% identified as transgender specifically. The higher percentage was due to increased challenges during the pandemic in getting the unique medications required by these LGBTQIA+ individuals.

“Estradiol valerate vials for injections have been scarce for years now, and this seems to have become even more profound during covid (though this may be happenstance). I spent weeks (without receiving a dose in the meanwhile) attempting to jump through hurdles with my healthcare provider, pharmacies, and online sources trying to get ahold of a vial. Compound pharmacies refused to make it as they claimed there was evidence of stock, while every major pharmacy attempted to order it only to send a notice a few days later that their supplier could not provide any. The only reason I was able to get a vial is one particularly dedicated pharmacist who kept on it throughout looking for sources (r117 – she/trans/bisexual, pansexual, queer).”

As such, some alternatives were prescribed as an attempt to work around the inaccessibility issues and prescription shortages. Some of the workarounds included switching from hormone replacement therapy shots to topical testosterone cream, which unfortunately impacted both the patients’ mental and physical health because of the abrupt change their body had a difficult time adjusting to the new medication. Worse still, such workarounds were not available to some of our respondents forcing them to go without their medication at all for some time until the pharmacy had stock again. One respondent described the multifaceted, unsuccessful attempt in securing their prescriptions and the subsequent physical toll on their body:

“I couldn't get an appointment with a trans clinic to save my soul. I saw an ad on Facebook for Planned Parenthood advertising trans care. I made an appointment. I had to download an app. I couldn't connect because the internet in my area was awful and [an internet provider] couldn't improve it for months. PP had no tech support line. I had to put a message into their portal to get them to call me. They refused to give me a regular phone appointment until I literally screamed at them. What should have been an hour-long appointment was a 20-minute appointment. I got T gel instead of shots because if I had wanted to get shots, I would have needed to schedule another appointment and no way in hell was I going to go through that again. I did not get good advice about microdosing. When changes happened too fast, I went off abruptly. A few days later, I almost threw myself off of a highway overpass. At least that got me an appointment with the trans clinic at one of the hospitals in my city. Literally. People just need to a) prioritize the care of the marginalized b) listen to, and believe us, the first time we tell them what we need and c) make themselves easy to access be it by phone, webcam, in person, whatever and d) give us reliable information. Reddit should not be more informative than someone who's spent \$300,000+ on med school (r13 – they/trans FtM/bisexual, pansexual, queer).”

Some respondents were unable to get their needed prescriptions due to transportation issues. For example, some had been relocated due to COVID-19 which forced them to have to drive to different towns to access their prescriptions. Others could not travel to a pharmacy that would accept their insurance. Others delayed getting their prescriptions until absolutely necessary because of the fear of exposure to the virus. Another respondent, who was forced to move back home with family due to the pandemic, had not filled or taken their prescription since returning home because they worried their family would discover their need for antidepressants. Another participant had been relocated to a different state which required them to get a prescription reconfirmation before they could get their prescriptions in the new state, making it more prone for them to forego their medications.

4.3.4 Healthcare

Twenty-five percent of our LGBTQIA+ respondents had trouble seeking health services due to COVID-19. Medical facilities, like LGBTQIA+ health centers, shut down and offered very limited or eliminated access entirely to in-person appointments. For many, in-person appointments were replaced by virtual consultations as safety regulations rendered the facilities closed or reduced their hours.

However, transgender people were negatively affected substantially by the reduction or elimination of in-person appointments because it also changed, reduced, or eliminated their access to their normal hormone replacement therapy. Some ended up with no hormone replacement medications at all. For others, it resulted in prescription changes that often involved transitioning from injectable hormones to an orally or topically administered hormone. As a result, many respondents experienced exceptional stress to the body, both physically and mentally, due to the sudden change or stopping of hormone treatments. Thus, the patients often needed additional care to combat the adverse effects.

Twenty-two percent of the general population experienced a reduction in mental health services during the pandemic [38], whereas over one-third of LGBTQIA+ respondents had their mental health appointments postponed or canceled due to the COVID-19 pandemic (Table 4-4). “Organizations have cancelled, rescheduled, or turned away 31.0% of patients” [39]. Nearly a quarter of our LGBTQIA+ survey respondents had their appointments canceled or postponed by their primary care providers (PCPs) due to the COVID-19 pandemic and one-third of our respondents have canceled or postponed appointments themselves with their primary care providers to minimize possible exposure to COVID-19. The LGBTQIA+ respondents had experienced a more significant reduction in access to health care than the general population [39] (Table 4-4).

4.3.5 Appointment Platform Changes

Our LGBTQIA+ respondents experienced an increased platform change with their mental health provider than they were with their primary care providers. In October 2020, 41% of the mental health appointments for the general population were conducted via telehealth after peaking at 50% in May 2020 [39, 40]. Ninety percent of our LGBTQIA+ respondents who received mental health care during the pandemic, experienced a change in the platform for their mental health appointments which was twice the number experienced by the general population [41]. Only 58% of LGBTQIA+ respondents had experienced a platform change with their primary care provider. The platform change rates, satisfaction levels and group comparisons can be found in Table 4-4.

Satisfaction Level.

Over 70% of our respondents were satisfied with their primary care provider's appointment platform change. Over 75% of our respondents who saw a mental health professional were satisfied with the change in platform, slightly less than the 80% satisfaction level of the general population [40, 42]. Eighty-two percent of our LGBTQIA+ respondents were satisfied with how their mental health professional handled the pandemic and 70% were satisfied with how their primary care providers did. Six percent of our LGBTQIA+ respondents were extremely dissatisfied with their mental health platform change and only 2% were extremely dissatisfied with their primary care platform change.

Benefits

Several benefits of telehealth were mentioned by our LGBTQIA+ respondents. Several respondents mentioned not having to commute or "fight traffic", thus reducing their travel time and the time needed off from work. Another respondent pointed out the cost savings from the

lack of travel and therefore transportation costs. Others experienced cost savings through waived insurance copays for telehealth and virtual visits.

Some respondents enjoyed maintaining their health through telehealth from the comfort and safety of their own homes. For other respondents, it created a nationwide pool of virtual LGBTQIA+ friendly and knowledgeable providers. It also empowered some LGBTQIA+ respondents with the ability to quickly end the well-documented condescending, discriminatory, or offensive interactions from both new and seasoned health professionals.

Drawbacks

Not all LGBTQIA+ respondents enjoyed the platform changes. Some respondents struggled with privacy issues; for them finding a private space for virtual health appointments was extremely challenging and sometimes impossible. For some the only way they knew how to ensure privacy from roommates and neighbor was to sit in their car during their virtual appointments.

Many LGBTQIA+ respondents felt the telehealth experience was impersonal, uncomfortable, and minimized the ability to read body language. A few respondents even deemed virtual health less productive than in-person:

“I experienced a few Tele-Medicine appts and they were okay. It felt like there were more barriers to connect with the physician but once we cleared those it was relatively fine. I flourish in in-person environments, especially when referring to or referencing my body/medical needs so the experiences were lackluster and didn't every really FEEL confident in how to move forward with recovery, etc.. (r147 – he/queer/gay, queer).”

The virtual or telehealth appointment experiences exhausted a few respondents more than their normal in-person appointments did. Our respondents who had experienced technical issues

became frustrated as some of their providers, in attempt to improve care, had constantly changed appointment formats, leaving the patient to struggle with new technology at each appointment.

4.4 Recommendations for Improving Healthcare Experiences during Pandemic

4.4.1 Technology Improvements

Despite their relatively young age and high education level, many LGBTQIA+ respondents experienced technology difficulties when interacting with their health care professionals virtually. For some, poor Internet connections and slow speeds affected their ability and experience in the virtual appointment; for others it was the poorly functioning video or telehealth software. In particular, technical support was often absent in these virtual platforms. Thus, timely technical support must be available to both healthcare providers and their patients before and during virtual appointments. In general, patients were not allowed to choose a platform that they feel comfortable with; this can greatly impact their experiences with virtual appointments. Thus, we recommend the option to allow patients to choose from multiple platforms for conducting virtual appointments.

Some respondents also criticized how disorganized the online meetings were. Some complained of the long wait times for virtual appointments; a few suggested displaying activities or educational health information pertinent to the patient while they were waiting.

4.4.2 Non-Technology Improvements

Most respondents were satisfied with how both their primary care and mental health providers handled the pandemic, making no suggestions for improvements and applauding their providers for keeping them safe. A few LGBTQIA+ respondents offered suggestions on how providers could improve care.

One of the suggestions made by our respondents was to improve health care access for the LGBTQIA+ community during a pandemic since the inability to get an appointment has left some feeling hopeless and desperate. Many respondents also felt that their providers could have improved their outreach to patients. For example, they would like their providers to actively check on how the pandemic was impacting their life and to offer more assistance including increased appointment availability and conveying important information like procedural changes due to COVID-19, hour reduction, staff reduction, change in format, and closures. They also wanted more post-appointment follow-up calls. Better and more frequent communication with healthcare providers was desired by many participants.

4.5 Conclusion

The study found, as we anticipated, that technology use to seek health information and services was greatly impacted by the COVID-19 pandemic for our LGBTQIA+ respondents, thus further increasing the health disparities they experienced during this vulnerable period. Many of our LGBTQIA+ respondents not only relied on technology for health information but, due to the pandemic, also depended on it for most of their other health needs. Our LGBTQIA+ respondents experienced a significant increase in health disparities due to COVID-19 including increased transportation barriers, inaccessible prescriptions, inconvenient appointment times, reductions in health services, and their mental health was negatively impacted.

The study found several unexpected findings. Despite a higher percentage of our LGBTQIA+ respondents being covered by health insurance, their self-assessed health statuses were lower than those of the general population. Surprisingly, only a few of our LGBTQIA+ respondents had lost their health insurance due to COVID-19. Yet due to enacted safety protocols and fears of the virus, they were still unable to access health services despite having

insurance coverage. Another surprising finding was the physical and mental trauma some of our LGBTQIA+ respondents suffered when they were unable to access their needed medications and health services.

Other studies have looked at the impact COVID-19 has had on the general population's access to health services and health information [23, 34, 35, 31, 37, 38, 39, 40]. Several have studied how the pandemic affected the mental health of the general population, but none have focused on the LGBTQIA+ population during the pandemic as ours did [12, 43, 28, 32, 36]. Many have studied LGBTQIA+ health and how it could be improved with technology, but that research was conducted before the impact of the pandemic and the new heavy reliance on technology for their health care [4, 16, 19, 22, 41, 42, 44]. Unlike earlier research, our study was able to investigate the impact COVID-19 had on LGBTQIA+ respondents' mental health, health services and the experiences they had with increased technology reliance for health needs.

The study found that the pandemic heavily impacted LGBTQIA+ respondents' technology use to seek health information and health services while simultaneously increasing health disparities within the community. Key findings should be used to improve access to health information and health services for the LGBTQIA+ community and to improve technology design to better serve both the LGBTQIA+ individuals and the general population.

In Chapter 5 if health care professionals are collecting and using gender identity, sexual orientations, pronouns, and other LGBTQIA+ related identifiers as part of the health record is investigated as is interviewees insight into if and how the topics of gender identity and sexual orientation should be approached by health care providers is also discussed, as are several considerations.

5 COLLECTION AND USE OF LGBTQIA+ IDENTITY DATA IN THE HEALTHCARE SETTING

The purpose of this qualitative study was to identify, through interviews the perceptions and experiences of LGBTQIA+ individuals, the challenges and barriers they experience when seeking health information and services and how they could be alleviated through improved or new technologies to improve care for the LGBTQIA+ community. In this chapter we investigate if health care professionals are collecting and using gender identity, sexual orientations, pronouns, and other LGBTQIA+ related identifiers as part of the health record as recommended by so many health institutions in the United States from interviewees in the study and the impact that has had on the health experience for LGBTQIA+ individuals [8, 9, 10, 11]. Interviewees insight into if and how the topics of gender identity and sexual orientation should be approached by health care providers is also discussed, as are several considerations.

The methodology used with participants for this chapter and the demographics of those who participated in our research study is discussed in detail in Chapter 3 subsections: 3.1 Methodology and 3.2 Participants' Demographics.

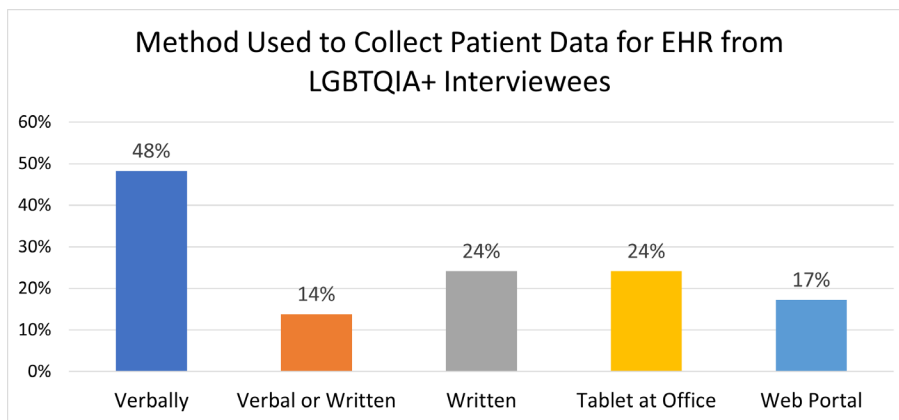
5.1 Patient Information Collection Methods Used for EHR

A variety and a combination of methods were used to collect information and data from the patient to be inputted into the electronic health record (EHR). Some of those interviewed had a few preferences on which method they preferred for a variety of reasons; others had no preference if it was private and secure.

A variety and a combination of methods were used to collect information and data from the patient to input into the EHR: verbal, written, and digital. Nearly half had their information collected verbally by an office person at their healthcare provider's office. Many stated that the

information was inputted as it was collected verbally into a digital system, usually via a computer or tablet. For some interviewees this method was fine if there was privacy. Others felt it allowed more nuanced responses to questions that when presented on paper the options were often limited. One downside, pointed out by some, to this method was that unless the healthcare provider confirmed them later there was no way to verify the correct information had been inputted.

Figure 5-1 Method Used to Collect Patient Data for EHR from LGBTQIA+ Interviewees



Almost one quarter of interviewees had their information collected via written form. A downside mentioned with this method was that the forms often did not provide adequate options for LGBTQIA+ interviewees to select from or offer enough opportunities to capture their full identities. To get around that, some wrote better identifiers in the margins. The same concern of not knowing if the information had been inputted correctly was held for written information, especially any additional notes made in the margins. Some stated their healthcare providers had used a paper form at their first appointment and at each subsequent visit verbally updated the information.

Nearly a quarter had their information collected with a tablet at the office. The duty of inputting the information into the tablet fell 57% of the time on the patient and the other 43% it

was collected by the healthcare provider who entered it into the tablet and verified it on subsequent visits. For some this was a singular experience; for others it was a routine collection method. Web portal input prior to an appointment was the least used method by interviewees. Only 17% had experienced this method.

A variety of methods are being used to collect patient information from interviews with the least technical methods being utilized the most frequently, despite a patient preference for digital technology use to collect the information. The information that was collected was as varying as the methods used to collect it.

5.2 Preferred Method for EHR Information Collection

While 24% of interviewees had no preference for the method used to collect patient information. An equal number of interviewees, 3.5%, preferred paper forms be used as did those who were afraid to make a mistake while using paper forms. Nearly 7% preferred information be verbally collected and yet another 3.5% preferred it either be collected verbally or written with no strong preference between the two. The heaviest preference amongst interviewees was for a digital method to be used to collect patient information for the EHR, especially one that could be done prior to the appointment. Despite only 41% of interviewees' information being collected in some form digitally, in office or prior to an appointment, 69% named it as the method they preferred. Some interviewees had specific devices they preferred the information be collected with tablet (10.3%), their own phone (10.3%), phone or website (6.9%), or only a website (3.4%).

Several reasons were given for the digital entry method preference. Nearly 21% desired the ability to input the information prior to the appointment at their convenience. The ability to correct errors and to see the exact information inputted into the system was mentioned by

interviewees as another reason for the digital preference. A small 3.5% of interviewees preferred digital entry because it was faster, more accurate, reliable, convenient, and 7% felt it was easier. For others, security and privacy were stated for the preference of digital information collection; preferring digital collection because it was safer (3.5%), encrypted (3.5%), private (3.5%), and secure (14%).

5.3 Collection of LGBTQIA+ Identity Information by Healthcare Providers

“They should be included because we are part of the society. It's just normal (p21 – he/trans/gay).” Collecting LGBTQIA+ related information for the electronic health record (EHR) was important for many participants. Respondents reported that their mental health provider was more likely than their primary care provider to collect information related to their LGBTQIA+ identity: preferred name, pronouns, gender identity, and sexual orientation.

Table 5-1 Percent of Healthcare Professionals Who Inquiry About LGBTQIA+ Identifiers

Percent of Healthcare Professionals Who Inquiry About LGBTQIA+ Identifiers (Survey Respondents)			
Preferred Name	Yes	No	Unsure
Primary Care Provider	49%	41%	10%
Mental Health Professional	61%	32%	6%
Pronouns	Yes	No	Unsure
Primary Care Provider	30%	60%	10%
Mental Health Professional	47%	37%	16%
Gender Identity	Yes	No	Unsure
Primary Care Provider	38%	56%	6%
Mental Health Professional	52%	44%	5%
Sexual Orientation	Yes	No	Unsure
Primary Care Provider	38%	51%	11%
Mental Health Professional	49%	41%	10%

5.3.1 Collection of Gender Identity Information by Healthcare Providers

“Would be the dream to say all right this is what I was born with, this is what I am currently working with, and what I identify as (p23 – she, they/still figuring gender out/bisexual).”

Most interviewees (65.5%) felt that gender identity should be collected by healthcare providers for the EHR. Yet less than half had their gender identity information actually collected, see Table 5-1. For 10% the information was collected but it was never acknowledged or used by providers to improve care. For some reason maybe discomfort, bias, or a lack of training may be some of the reasons healthcare providers are not collecting this information.

Some (10.3%) interviewees, who were transgender or demigender, felt that gender identity was needed by some and not needed by other health specialists as it was not pertinent to the health issue being addressed by those providers: dermatologists, chiropractors, dentists, cardiologists. A bisexual cisgender interviewee felt gender identity information should not be collected by healthcare providers *“not really necessary asking that” “should skip these questions move on to the essential questions (p16 – he/cis/gay).”*

Despite growing acceptance most were still not comfortable disclosing to everyone their LGBTQIA identity, including their healthcare providers. Only 31% of interviewees and 57% of respondents considered themselves fully out – indicating that society is still not that welcoming and accepting of the LGBTQIA+ community. Over 14% would not disclose their LGBTQIA+ identity to healthcare providers even if asked due to their fear of discrimination. This fear was justified, as 72% of interviewees had been discriminated against by a healthcare provider because of their LGBTQIA+ identity. Despite this risk, for the rest of interviewees felt collecting this information was important data for their healthcare.

For some interviewees providing gender information was not only important but essential, otherwise there was potential for them to be misgendered, gendered, or for healthcare providers to *“not be sensitive to certain things (p20 – they/non-binary/pansexual, bisexual)”*. Others expressed it was the only way for a healthcare provider to know all the layers of their

health needs “*to figure out how to help (p22 – she/trans/straight)*” and to allow them to “*know the ways they are going to handle your health matters (p5 – he/cis/gay)*”.

“Technically, I am a woman in every way, shape, and form. What any other 75-year-old woman would be except I have a prostate and the doctor needs to know that to properly diagnose me, to properly treat me (p1 – she/trans).”

Discomfort in disclosing the nuances of sex at birth and gender identity was expressed by a few interviewees, but some stated the importance of that information being collected despite their discomfort disclosing it.

“Uncomfortable as it makes me to have these conversations, I do understand that there is a biological sex component to medicine that is important” “I was not born as a cisgendered woman, and I do not have like my physiology is different so like I understand why they asked those questions, but the way that they do currently is in such a way that it's very unsettling (p19 – she/trans/pansexual).”

The approach to sex at birth and gender identity information collection by healthcare providers should be done very thoughtfully and only after the healthcare provider has been educated on the differing identities; “*I do think that there should be both [sex & gender] included, but that the doctor should be educated on what that means (p19 – she/trans/pansexual).*” Gender identity, pronouns, preferred names, and questions related to the patient’s name should be used, “*What is your preferred name? (p1 – she/trans)*”, “*Does your preferred name match your legal name (p19 – she/trans/pansexual)?*” to allow a fuller picture of the patient’s identity.

Nearly 45% of interviewees felt having a fill-in option for gender identity would be the easiest way to provide inclusive care, almost 38% wanted a more robust lists of gender options in addition to the fill in blank option. Nearly 38% preferred to have a private discussion with their healthcare professional about this information instead of disclosing it on a form or to a device.

Sexual orientation collection was considered by many to be not as necessary information as gender identity, pronouns, and preferred name. Some stated that more pertinent questions would be “are you having sex” “what kinds” “with WHO” and if using contraceptives. But for some this too was a pertinent question to help avoid awkward interactions and to facilitate better care. Most participants felt that their LGBTQIA+ identifiers were important and needed to be collected for improved health care.

5.3.2 Other Considerations

Our research found that there are several considerations to consider with the collection and use of LGBTQIA+ identifiers in the medical setting. Nearly 14% of interviewees were trans but wished not to be identified or labeled as such as they identified only as male or female not trans male or trans female. The fear of the information being used for discriminatory purposes was expressed by over 17% of interviewees. The fear of discrimination, a justifiable one with 72% having already experienced, would need to be addressed through some manner prior to their disclosure.

Gender identity, sexual orientation, and pronouns are often fluid according to the participants of our research study. Some were fluid with their pronouns in all settings; for others, time, place, and people present shaped their pronoun use. Fluidity of pronoun use allowed some participants to evade possible discriminatory interactions and the additional work of explaining or defending their identity. *“I use different pronouns in different spheres. I settled on “they/them” in online spaces because it means both “plural” and “unknown.” In IRL/professional spaces I just go with she/her because they/them is too much work to put myself through (r142-she, they/gender queer/pansexual, queer).”*

Many noted that one’s pronouns are not ‘preferred’ and should not be referred to as such. Many respondents’ and interviewees stated their gender and/or sexual orientation had changed during their lifetime. Of the survey respondents 56% said their sexual orientation had changed over their lifetime and 44% said their gender had changed over their lifetime.

LGBTQIA+ Identification Changed Over Lifetime		
	Interviewees (29)	Survey Respondents (155)
Gender Identity	31%	44%
Sexual Orientation	7%	56%
Pronouns	14%	7%

The indicated fluidity of sexual orientation, gender identity, and pronouns suggests these identifiers need to be routinely collected and frequently updated to reconfirm their correctness. These identifiers need to be approached more than once as is often currently done by both providers and technologies.

5.4 Conclusion

A variety and a combination of methods were used to collect information and data from the patient to input into the EHR: verbal, written, and digital. The least technical methods were utilized the most frequently, despite patients’ preference for digital technology use to collect the information. The identity information that was collected was as varied as the methods used to collect it. Collecting LGBTQIA+ related information for the EHR and using it in health care was important for many participants despite it not being done regularly by health providers, leaving patients to feel unseen and fearing discrimination. Many suggested using a list to choose from with a fill-in option to be most inclusive. The indicated fluidity of sexual orientation, gender identity, and pronouns suggest these identifiers need to be routinely collected and frequently updated to reconfirm their correctness in the electronic health record. Some LGBTQIA+

individuals were so fearful of discrimination they will not disclose their full identity to their health providers under any circumstances.

6 CONCLUSION

This research raises several new questions that could improve health information and services seeking and health care access for the LGBTQIA+ community. Fostering the use and collection of LGBTQIA+ identity information for the electronic health record by health care providers could improve inclusivity not only in the healthcare setting but also online, thus making health information and services easier to find for the LGBTQIA+ community. Several recommendations have been made based on the research findings:

- Develop a national database of knowledgeable healthcare providers.
- Develop a mechanism or a database to ensure accurate and credible health information.
- Improve social media websites to address the temporary nature of health information.

6.1 Research Problems and Summary

The LGBTQIA+ community has historically struggled to access LGBTQIA+ related health information, services, and care. Despite the gradually growing acceptance, the LGBTQIA+ community still experiences exclusions, prejudices, and discrimination when seeking health information and services [1, 2, 3, 4, 5, 6]. The purpose of this qualitative study was to identify, through the perceptions and experiences of LGBTQIA+ individuals, the challenges and barriers the LGBTQIA+ community experiences when seeking health information and services and how they could be alleviated through improved or new technologies to improve care for the LGBTQIA+ community.

Previous research has shown that a lack of inclusive design negatively impacts health accessibility for LGBTQIA+ individuals. While LGBTQIA+ inclusivity improves relationships with health providers and optimizes care by underpinning health care customization. Not collecting LGBTQIA+ identity information compounds health data inaccuracies and

inaccessibilities. Simply using a more inclusive set of LGBTQIA+ identifiers normalize the collection and interaction with such identities while reducing disparities and discrimination experienced by the LGBTQIA+ community. It is imperative for optimal health care that LGBTQIA+ identity information be collected and used by healthcare providers.

Our study used the lived experiences of participants to better identify and understand the challenges and barriers LGBTQIA+ individuals experience when seeking and accessing health information and services. Anonymous surveys (n=155) and interviews (n=29) were used to ask both close-ended quantitative and open-ended qualitative questions to explore how LGBTQIA+ individuals currently navigate and seek health information. Affinity diagramming was used on the qualitative data and statistical analysis was conducted on the quantitative data.

6.2 Limitations

Our sample was not representative of the population demographics in the U.S. with respect to age, race, ethnicity, and education level. The racial and ethnic makeup did not align with the respective ratios in the general population found by the US Census Department [44]. Caucasians and Asians were overrepresented and Black, Hispanics, and Native Americans were underrepresented in our survey sample, as indicated in Table 3-1. Blacks were overrepresented while Whites and Hispanics were underrepresented in our interview sample. Our study's cohort was very young, 62% of our respondents were under the age of 35 and 77% were under the age of 45, and they were highly educated. These two factors may have increased their comfort level with and use of technology. In both our sample groups, marital statuses were not representative of the U.S. general population; this was expected as the LGBTQIA+ community has just recently received the right to have their marriage legally recognized nationwide in 2015.

Our study had several limitations that should be considered. Due to the pandemic, respondents were only recruited via digital technology like emails and digital flyers. Therefore, we may have left out those who are less tech-savvy and those who have limited to Internet access. This may also explain why many of our respondents were young, highly educated, and comfortable with technology. Future research should include those who are less tech-savvy such that they may not use technology for their health needs and those who do not have reliable access to the Internet.

6.3 Contributions

The current research makes the following contributions:

1. A set of strategies and resources that LGBTQIA+ individuals used to seek health information.
2. Factors on why the Internet is frequently used for seeking health information and services and the associated challenges.
3. Frequently used strategies to determine health information accuracy and credibility.
4. Gaps in the design of voice assistant technology to support health information seeking.
5. Challenges encountered in health information and services seeking during the COVID-19 pandemic.
6. The importance of collecting accurate information on sexual orientation and gender identity to LGBTQIA+'s healthcare.
7. The need for a national database of LGBTQIA+ knowledgeable healthcare providers, listing their LGBTQIA+ knowledge qualifications to improve access and care.
8. The need for education about the LGBTQIA+ community and their health needs for healthcare providers and supporting personnel.

6.4 Future Works

Several areas show promise for future research from our findings:

6.4.1 Foster Use of LGBTQIA+ Identity Information by Health Care Providers

Fostering the use of LGBTQIA+ identifiers would improve health care and patient-provider relationships. Research should be conducted with health care providers to better understand why they are not and how to get them to collect and use LGBTQIA+ identifiers. Understanding through research what would be needed from a digital education program for healthcare providers and their staff to learn about the LGBTQIA+ community, their health needs, and the importance of collecting and using LGBTQIA+ identity information. By determining how to increase the use of LGBTQIA+ identifiers, one may also be able to improve access to health information and services for the LGBTQIA+ community by connecting the needed information to the niche identifier allowing them to find it easier online.

6.4.2 Develop Provider Knowledge Level Classification System

Determine how best to design a provider knowledge level classification system using input from the LGBTQIA+ community and if the community would see a benefit to this type of system. Through user-centered research, create a LGBTQIA+ knowledge rating system that allows patients to quickly know the experience and knowledge level of their health care provider. This would be very beneficial for the LGBTQIA+ community in aiding their ability to find not only LGBTQIA+ friendly but knowledgeable providers.

6.4.3 Create a National Database of LGBTQIA+ Knowledgeable Providers

One of the hardest tasks LGBTQIA+ participants faced was finding LGBTQIA+ knowledgeable health care providers. User centered research should be conducted to determine

what information the LGBTQIA+ community would want and need from a national database of LGBTQIA+ knowledgeable health care providers. Healthcare providers training, certifications, experiences, and reviews could be components to help LGBTQIA+ individuals select the best provider for them. Research to understand how to best promote it and gain participation from both healthcare providers and LGBTQIA+ patients alike. Database development would help LGBTQIA+ individuals access healthcare providers who could provide them with the best care and minimize the chance of discriminatory encounters while seeking healthcare.

6.4.4 Improve Social Media Sites Design to Facilitate Health Information Sharing

Despite social media's frequent use for LGBTQIA+ health information, its ephemeral design makes finding and sharing health information difficult and should be addressed in some way. Search functions, sharing abilities and sorting by chronological order should be improved to facilitate the access of health information for the LGBTQIA+ community. Research should be conducted to better understand how social media and its design could be improved to further facilitate its use as a health information source for the LGBTQIA+ community.

6.4.5 Ensure credible and accurate health information

One of the big challenges LGBTQIA+ individuals faced was determining accuracy and credibility of health information. Research the best ways to help LGBTQIA+ individuals determine accuracy and credibility of health information: a mechanism to verify, a website or some other method. Should a mechanism be created to ensure the credibility of LGBTQIA+ health information online; would one be used? Many participants suggested developing a user-friendly, credible, and accessible LGBTQIA+ focused health website, like WedMD, for the community to use. Research should be conducted to better understand what would be needed

from a LGBTQIA+ health information site and the average health literacy of the user to make it as user friendly as possible. Research what method(s) would improve access to credible health information for the LGBTQIA+ community.

6.5 Conclusion

Even with increased acceptance, the medical world still falls short in the inclusiveness of the LGBTQIA+ community, and the lack of its use is drastically impacting both their provider-patient relationships and access to health information and services. Collection and use of LGBTQIA+ identity information in the health record would normalize its use and could improve LGBTQIA+ inclusivity, overall care, presence in the health information available and the ability to access health information and services. This research study motivates the future creation and improvement of technologies that could dramatically improve access to health information and services for the LGBTQIA+ community.

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APPENDIX A: GLOSSARY

Asexual: people who do not experience sexual attraction or desire [45].

Antiretroviral (ARV): drugs used to treat and prevent HIV

Bisexual: means to be attracted to two genders, the same gender, and others [45].

Cisgender refers to those whose gender match the sex and gender they were assigned at birth, in our society this has historically been the assumed “norm” of individuals.

“Closeted”: refers to not publicly disclosing their LGBTQIA+ identity [45].

“Coming out of the closet”: occurs when they publicly begin to announce their LGBTQIA+ identity [45].

Demisexual: someone who only experiences a sexual attraction to people they have a strong emotional connection with [45].

Gay: individuals are sexually attracted to the same sex or same gender as themselves [45].

Gender: “generally refers to the cultural, social, and psychological meanings of femaleness and maleness [46].”

Heterosexual: also known as straight, is someone who is attracted to their opposite sex or gender, a male and female couple.

Heteronormative: refers to the concept that “denotes the informal and institutionalized forms of power that establish heterosexuality as the only legitimate form of sexual being” making it the perceived norm for sexual orientation within our society and culture [47].

HPV or Human papillomavirus infection: another STI, “is a group of more than 200 related viruses, some of which are spread through vaginal, anal, or oral sex [48].” All sexes can become infected with HPV. Some of the variants can lead to cancer later in life, a vaccine has been developed to prevent HPV infection and therefor the resulting cancer.

Intersex: people are “born with variations of sex characteristics that may involve genital ambiguity and/or combinations of chromosomal genotypes and sexual phenotypes other than XY-male and XX-female [45]”.

Interviewees: LGBTQIA+ individuals who participated in a Zoom interview with Taylor Schell Martinez.

Lesbian: is a woman who is sexually and emotionally attracted to another woman [45]. Lesbians often also consider themselves gay.

LGBTQIA+: is an inclusive umbrella term for all non-heteronormative gender identities and sexualities [45].

Pansexual: a person who is attracted to people of all genders and sexualities [45]. Sometimes bisexual and pansexual terms are used interchangeably and is often done so by individuals who identify as pansexual but only because bisexual is the closest identity option available to choose from and a well-known term.

Participants: all LGBTQIA+ individuals who participated in research study. Includes both interviewees and survey respondents’ groups.

PEP: an antiretroviral (ARV) drug used to treat and prevent a specific STI, HIV.

PREP: an antiretroviral (ARV) drug used to treat and prevent a specific STI, HIV.

“Out”: refers to being openly and publicly LGBTQIA+, “outness” or “coming out of the closet” occurs when they publicly begin to announce their LGBTQIA+ identity [45].

Queer: is an umbrella term to describe anyone who is not heterosexual and/or cisgender [45].

Respondents: LGBTQIA+ individuals who completed the online Qualtrics survey.

Same-gender loving: individuals are attracted to the people of the same gender [45].

Sex or biological sex: refers to the chromosomal genotypes, sexual phenotypes, and reproductive organs that one has.

Sex assigned at birth: refers to the sex assigned by doctors at birth. For many this stays the same throughout their lives and matches their gender, for others it does not match their gender identity, or they were misassigned at birth due to being intersex.

STIs: are sexually transmitted infections and refer to what used to be called STDs or sexually transmitted diseases.

Trans: a person whose gender is different than the sex they were assigned at birth [45]. Trans is often used to describe those who do not necessarily fit the sex they were assigned at birth but do not feel they identify as the opposite gender either, they tend to be non-binary, genderfluid, etc. Trans can also be used as an umbrella term to include both trans and transgender individuals. In our research use trans as an umbrella term but distinguish when do so versus using it as a specific term to minimize confusion.

Transgender: a person whose gender is different than the sex they were assigned at birth [45]. Transgender is often used to refer those who identify as the opposite gender as they were assigned at birth. Trans and transgender are often used interchangeably, as it is throughout our research, but we quickly found out they are not interchangeable for many who identify as only one and not the other.

APPENDIX B: INTERVIEW STUDY ARTIFACTS

This appendix contains the interview protocol, question set, along with its logic, and compensated participant recruitment flyer used with interviewees between February 2021 and September 2021.

B.1 Interview Protocol

[Participant initially enters Zoom waiting room and is moved to main meeting. Interview begins once Zoom says they are fully connected.]

Good afternoon/evening.

My name is Taylor Martinez I am a graduate student in computer science at the University of Michigan Flint and I will be conducting the interview today. [participant may respond]

I want to start off by thanking you for agreeing to participate. [participant may respond]

Before we get started, I want to verify that I have your consent to record this interview?
[participant responds]

This interview will discuss some of your experiences with medical providers, health information seeking, health related technologies and health insurance. Did you have a chance to read the consent information sheet? [participant responds]

As it stated, your responses will be kept completely confidential and will be anonymized through transcription. The interview may ask questions that are considered sensitive in nature. You do not have to answer any questions you do not feel comfortable answering. I want to also remind you that your participation in this interview, and your consent to recording it, is completely voluntary and you are welcome to change or end your participation or your consent to recording at any time during the interview, just let me know if you wish to do so. [participant may respond]

Please keep in mind there are also no wrong or right answers and not having an answer or an experience is perfectly fine. Do you have any questions for me before we get started? [participant responds]

B.2 Interview Question Set

Demographics

Is this your first time participating in this interview?

1. How old are you?
2. What identification(s) make you a member of the LGBTQ+ community?
3. What state do you live in in the United States?
4. What is your racial and ethnic identity?
5. What is the highest level of education you have achieved?
6. Are you employed?
7. What is your main form of transportation?
8. Is it a reliable source of transportation?
9. **[IF NO]** Can you explain why or how it is not reliable?

10. LGBTQ+ Identity

11. How do you identify your current sex and gender identity?
12. Have these changed over your lifetime? **[YES / NO]**
13. **[IF YES]** Can you explain or describe how it has changed?

14. What are your pronouns?

15. What is your sexual orientation?

16. What is your current marital status?

17. As a LGBTQ+ individual, can you explain how out you are to everyone, family/friends, public/private? Explain.

Health Info Seeking Behaviors

18. How would you describe your current overall health status?
19. What strategies do you use when seeking health information: medical professionals, the library, a LGBTQ+ center/organization, family, friends, internet?
20. Can you explain why you use this method?
21. How satisfied are you with this method?
22. Do you have any suggestions for improving it? **[YES / NO]**

23. Have the strategies you normally use to seek health information changed due to the COVID-19 pandemic? **[YES / NO]**
24. **[IF YES]** Can you explain or describe how they have changed?
25. Are you satisfied with this new method? **[YES / NO]**
26. Can you elaborate?

27. What health related topics have you researched online general health, LGBTQ+ related, sexual health, procedures, fitness, nutrition?

28. Can you explain why you research those topics online?
29. Are there any online sources you tend to seek health information from and can you explain why? Are they topic specific? do you find the information reliable and accurate?
30. Are there any online sources you avoid when seeking health information from and can you explain why?
31. Are there any health topics that you solely seek information online for? **[YES / NO]**
32. **[IF YES]** What topics are they?
33. Can you explain why you solely seek that information online?
34. Are there any health topics that you will NOT research online? **[YES / NO]**
35. **[IF YES]** What topics will you not research online?
36. Can you explain why you will NOT seek that information online?
37. Are there any health topics that you feel are **easier** to find information on? **[YES / NO]**
38. **[IF YES]** What are they?
39. Can you explain why you feel the information is **easier** to find?
40. Are there any health topics that you feel are **harder** to find information on? **[YES / NO]**
41. **[IF YES]** What are they?
42. Can you explain why you feel this type of information is **harder** to find?
43. When you find health information online, do you find that information to be productive, accurate, and helpful? **[YES / NO]**
44. Are you able to find online health information geared toward LGBTQ+ individuals? **[YES / NO]**
45. Explain (more of one type)
46. Are you able to find online health information from a LGBTQ+ individual's perspective? **[YES / NO]**
47. Explain (more of one type)
48. Have you found any differences between seeking general health information, mental health information and LGBTQ+ focused health information?
49. **[IF YES]** Can you explain the differences you have experienced?
50. Are your health information needs being met in all areas (mental health, general health LGBTQ+ specific school, family planning, sexual health, health insurance)?
51. **[IF NOT]** Can you explain where they are not being met?
52. Do you have any suggestions for improving access to health information for LGBTQ+ individual's?

53. Please describe any other challenges or barriers you have experienced when seeking health care information.
54. Can you suggest ways health and medical information seeking may be made easier for you as a member of the LGBTQ+ community?
55. *Do you discuss LGBTQ+ focused health topics as often with family and friends as you do general health topics? Can you explain why or why not?*
56. *Do you discuss mental health topics as often with family and friends as you do general health topics? Can you explain why or why not?*

Technology use

57. Have you ever used a smartwatch or other wearable smart device? **[YES / NO]**
58. **[IF YES]** Which ones?
59. What was your experience like when using a smart watch?
60. Have you ever used other non-wearable smart devices like speakers, security cameras, appliances, switches, plugs, or lighting? **[YES / NO]**
61. **[IF YES]** What devices have you used?
62. What was your experience using these devices like?
63. Do you use a voice assistant (Siri, Alexa, Google Assistant, Bixby, Cortana, S voice, etc.)? **[YES / NO]**
64. **[IF YES]** Which ones?
65. Do you use the voice assistant for health information and healthcare needs? **[YES / NO]**
[IF YES] How do you use it in relation to your health and healthcare?
66. Can you describe any challenges you have experienced when using a voice assistant to seek health information?
67. **[IF NOT]** Can you explain why you do not use it for health-related activities?
Any suggestions for improving its health-related uses?
68. Have you ever received medical test or lab results via mobile application or website? **[YES / NO]**
69. **[IF YES]** What was the experience like?
70. Is this different since COVID? **[YES / NO]**
[IF YES] Can you explain how it is different?
71. *What methods do your health providers use to collect your information at/for appointments verbally, via a paper form or through a digital device?*
72. *How do you feel more comfortable disclosing information to your medical care providers at intake? By writing it on paper, inputting it digitally or telling a medical profession in*

person? Can you explain why you feel most comfortable with that method and not the others?

73. *When categorizing by **sex** on medical forms and in health applications, what sexes do you think should be included/used?*

74. *Should gender identity be collected in health-related care, technologies, and information?*

75. *If the category for **gender** is present, what gender options do you think should be included?*

Health Insurance

76. Are you currently covered by health insurance or coverage plans? **[YES / NO]**

77. **[IF YES]** What is the source?

78. **[IF NOT]** Why not?

79. Did your health insurance coverage change due to the COVID-19 pandemic? **[YES / NO]**

80. **[IF YES]** Can you explain how and why it changed?

81. Are all your LGBTQ+ related health needs covered by your insurance? **[YES / NO]**

82. **[IF NOT]** What LGBTQ+ related health needs **ARE NOT** covered by your insurance?

83. Have any of your LGBTQ+ related health needs been considered preexisting conditions or required a referral to address? **[YES / NO]**

84. **[IF YES]** Can you explain what wasn't covered, why and any workarounds used.

Prescriptions

85. Have you had problems getting prescription medicines since the COVID-19 pandemic started? **[YES / NO]**

86. **[IF YES]** Can you describe the experience.

87. How was it dealt with or worked around?

88. Have you had to change the method you use to get your prescriptions and medical devices from the pharmacy due to COVID-19 (for example no longer going to the pharmacy but having them delivered)? **[YES / NO]**

89. Have you **EVER** had to secure your prescribed medication from sources other than a doctor, pharmacy, or other medical facility? **[YES / NO]**

90. **[IF YES]** Why did you have to secure from another source?

91. Have you ever **not** taken prescribed medicine because you could not afford to purchase the medication? **[YES / NO]**

Mental Health Provider

92. Have you ever researched mental health information online to find out more about it?
[YES / NO]

93. Do you use any applications or programs to help with your mental health like meditation apps, mindfulness apps, mental health, LGBTQ+ specific mental health, support group apps)? **[YES / NO]**

94. **[IF YES]** Which types and apps?

95. Are there any features you really like or really dislike? **[YES / NO]**

96. Are there any improvements you would make?

97. Do you see a mental health provider? **[YES / NO]**

[IF NOT] SKIP TO PRIMARY CARE SECTION

98. **[IF YES]** For how long have you been seeing them?

99. How did you find them?

100. Would you consider them to be LGBTQ+ friendly and can you explain why?

101. Has your mental health provider asked about your gender identity, sexual orientation, preferred pronouns, and nicknames? **[YES / NO]**

102. Do you feel your mental health provider and their staff acknowledge and respect your LGBTQ+ identity? **[YES / NO]**

103. **[IF NOT]** Explain.

104. Do you feel your mental health provider is sensitive to and knowledgeable about your mental health needs as a LGBTQ+ person? **[YES / NO]**

105. **[IF NOT]** Explain.

106. What formats do you use to interact with your mental health professional (in-person, virtual, text, email, online)?

107. How satisfied are you with this format?

108. Has the format you use to interact with them changed since COVID? **[YES / NO]**

109. Explain how the format changed and how satisfied with this new format you are.

110. Has the COVID-19 pandemic affected your mental health care: canceled or postponed appointments, appts harder to come by, etc? **[YES / NO]**

111. How satisfied were you with your mental health professional's overall response to the COVID-19 pandemic?

112. What suggestions, if any, would you make to your mental health professional to improve their response to COVID-19 and allow for a more seamless mental health care process?

Primary Care Provider

113.Have you ever not seen a medical professional because you could not afford it? **[YES / NO]**

114.**[IF YES]** When? Can you explain.

115.Have you ever stopped using a medical professional because you felt you were discriminated against because of your LGBTQ+ identification or your LGBTQ+ identification was not acknowledged? **[YES / NO]**

116.**[IF YES]** When?

117.Can you describe your experience?

118.Have you ever been denied health care or health information because of your LGBTQ+ identification? **[YES / NO]**

119.**[IF YES]** When?

120.Can you describe your experience?

121.Do the medical professionals you interact with ask about your gender identity, sexual orientation, preferred pronouns, and nicknames as part of your medical records? **[YES / NO]**

122.Do the medical professionals you interact with and their staff acknowledge and respect your LGBTQ+ identity? **[YES / NO]** Explain. **[IF YES]** When?

123.Do you feel the medical professionals you interact with and their staff are sensitive to and knowledgeable about your medical health needs as a LGBTQ+ person? **[YES / NO]**

124.Can you explain why you feel that way?

125.What formats do you use to interact with your medical professional (in-person, virtual, text, email, online)?

126.Explain.

127.Has the interaction format changed due to COVID?

128.How did the format change?

129.How satisfied with this new format are you?

130.Are there any other ways the COVID-19 pandemic has affected your medical care: canceled or postponed appointments, appts harder to come by, etc? **[YES / NO]**

131.How satisfied were you with your medical professional's overall response to the COVID-19 pandemic?

132.What suggestions, if any, would you make to your medical professional to improve their response to COVID-19 and allow for a more seamless health care process?

133.Is there anything I missed that you can think of that relates to your experience to health care, health information and technology?

This completes our interview.

[for those being offered compensation]

To thank you for your time today you will receive a \$25 Amazon virtual gift card. I just need to verify your email address you would like to receive it at.

[would state email address and type it into Zoom's chat to verify correct]

I want to thank you again for taking time to out of your schedule to participate and for sharing your experiences with our study. Your input helps make truly inclusive and representative design one step closer to a reality.

[end Zoom meeting for all]

B.3 Interview Consent and Information Sheet

This consent and information sheet was emailed to each participant for them to read prior to the interview. At the beginning of the interviewees were asked if they had read the consent and information sheet and gave their consent to participate in the interview as detailed in it.



COLLEGE OF ARTS & SCIENCES COMPUTER SCIENCE

INTERVIEW INFORMATION SHEET

AN INVESTIGATION INTO HOW LGBTQ+ INDIVIDUALS USE TECHNOLOGY TO SEEK
HEALTH INFORMATION AND SERVICES.

HUM#00188636

Principal Investigators: Taylor S. Martinez (MS student) and Dr. Charlotte Tang (Associate Professor), Department of Computer Science, University of Michigan-Flint

You are invited to participate in a research study investigating how LGBTQ+ individuals use technology to find health information, seek health services and interact with their medical care professionals. The goal of this study is to identify challenges and barriers LGBTQ+ individuals may experience when seeking health information and accessing health care services and how these challenges may be alleviated through technological solutions.

If you agree to be part of the research study, you will be asked to participate in a recorded phone interview that will take approximately 45-60 minutes to complete. The interview will collect information about your general demographics and identity information, how you use technology to find health information, seek health services and interact with your medical care professionals and how that usage may have changed since the COVID-19 pandemic.

Benefits of this research is a one-time payment of a \$20 gift card to you, the participant, for your time spent participating in the interview. Other benefits may not be direct or immediate to you, the participant, but your participation will help us identify issues for improving the health information system and health services, which will benefit your health care in the long run.

Risks and discomforts from the research study are minimal. The research team does not foresee or anticipate any direct risk to the subjects for their participation.

Compensation is contributing to the improvement of technology and the sincere gratitude from the research team for your participation. There is no financial incentive or compensation for participation in the interview.

Participating in this study is completely voluntary. Even if you decide to participate now, you may change your mind and stop at any time. You may choose not to continue with the interview for any reason, at any point during the interview. If you choose to stop participating, the information gathered until that point will not be used in the research study and will be destroyed immediately.

We will protect the confidentiality of your information by storing any data collected safely on a secured university network. For the purpose of data analysis, we would like to audio-record the phone interview. Only the investigators of this study will have access to the recordings. The audio-recordings will also be stored on a secured university network for three years after the study and then will be permanently erased. Participants' identity will be protected by masking it with an alias in all other data, publications, and presentations. The audio recordings will be transcribed into a text document for analysis with participants identified by the aliases only, permanently de-identifying the responses. The de-identified transcriptions of the audio-recordings will be stored indefinitely.

Information collected in this project may be shared with other researchers, but we will not share any information that could identify you.

If you have questions about this research study, please contact Taylor S. Martinez, 207 Murchie Science Building, 810-762-3131, tschell@umich.edu or Dr. Charlotte Tang, 207 Murchie Science Building, 810-762-3184, tcharlot@umich.edu.

As part of their review, the University of Michigan Institutional Review Board Health Sciences and Behavioral Sciences has determined that this study is no more than minimal risk and exempt from on-going IRB oversight.

B.4 Interview Recruitment Flyer

This was the flyer used to recruit participants for the compensated interview (uncompensated interview recruitment used the same flyer as the survey recruitment). Most reached out from email and there were no direct emails sent to solicited participants



COLLEGE OF ARTS & SCIENCES COMPUTER SCIENCE

AN INVESTIGATION INTO HOW LGBTQ+ INDIVIDUALS USE TECHNOLOGY
TO SEEK HEALTH INFORMATION AND SERVICES.

HUM#00188636



****Call for LGBTQ+ identifying adults**



to participate in a PAID Interview (\$20 gift card)**

If you self-identify as LGBTQ+, are over the age of 18 and live in the United States, we are looking for your input...

We are researchers at the University of Michigan – Flint’s Computer Science Department and we would like to invite you to participate in a study to investigate how technologies are used by LGBTQ+ individuals when seeking health information and services. Our goal is to improve access to accurate, relevant health information and health care for the LGBTQ+ community. If you would like to participate, there are 2 ways you can do so...

- ✓ An interview. I am looking for LGBTQ+ identifying individuals to participate in a 45–60-minute confidential Zoom interview about their experiences interacting with health professionals, seeking health information and using health technologies. Those who participate in the interview **will be compensated with a \$20 Amazon gift card** for their

time at the end of the interview!!! Please contact Taylor at tshell@umich.edu to schedule your interview today!

OR

- ✓ An unpaid survey. You can take our online survey from the comfort and privacy of your own home. The survey will take approximately 20 minutes of your time to complete and can be found at go.umflint.edu/LGBTQTechSurvey

We respect your privacy, so any information collected will be kept completely confidential. Find the information and consent forms here

Survey go.umflint.edu/LGBTQTechSurveyConsent

Interview go.umflint.edu/LGBTQTechInterviewConsent

We look forward to hearing about your health information and care seeking experiences.

APPENDIX C: SURVEY STUDY ARTIFACTS

This appendix contains the question set, along with its logic used on Qualtrics for the survey, the recruitment flyer and recruitment email body used with survey respondents.

C.1 Survey Question Set

This was the survey question set and logic used on Qualtrics to conduct all surveys. Consent to participate and information detailing what exactly that meant was the first question respondents were asked to complete. Not all questions were answered, depending on previous answers, by all respondents.

LGBTQIA+ Health Information Seeking and Technology Use Survey

Survey Flow

Standard: Survey Consent (1 Question)
Standard: Demographic Information (5 Questions)
Standard: LGBTQ+ Identity information (11 Questions)
Standard: Seeking Medical and Health Information (16 Questions)
Standard: General Health Information (7 Questions)
Standard: Health Insurance (8 Questions)
Standard: Mental Health Information (19 Questions)
Standard: Primary Health Provider (14 Questions)
Standard: Voice Assistants (7 Questions)
Standard: Interview promo (1 Question)

Page Break

Start of Block: Survey Consent

Q1.1 An Investigation into How LGBTQ+ Individuals Use Technology to Seek Health Information and Services (HUM#00188636) Principal Investigators: Taylor S. Martinez (MS student) & Dr. Charlotte Tang (Associate Professor), Department of Computer Science, University of Michigan-Flint

You are invited to participate in a research study investigating how LGBTQ+ individuals use technology to find health information, seek health services and interact with their medical care providers. The goal of this study is to identify challenges and barriers LGBTQ+ individuals may experience when seeking health information and accessing health care services,, and how these challenges may be alleviated through technological solutions.

If you agree to be part of the research study, you will be asked to participate in an anonymous online survey that will take approximately 20 minutes to complete. The survey will collect information about your general demographics and identity information, how you use technology to find health information, seek health services and interact with your medical care providers, and how that usage may have changed since the COVID-19 pandemic.

Benefits of this research may not be direct or immediate to you, the participant, but your participation will help us identify issues for improving the health information system and health services, which will benefit your health care in the long run.

Risks and discomforts from the research study are minimal. The research team does not foresee or anticipate any direct risk to the subjects for their participation in this anonymous online survey.

Compensation is contributing to the improvement of technology and the sincere gratitude from the research team for your participation. There is no financial incentive or compensation for participation in the survey.

Participating in this study is completely voluntary. Even if you decide to participate now, you may change your mind and stop at any time. You may choose not to continue with the survey for any reason, at any point during the survey. If you choose to stop participating, the information gathered until that point will not be saved or used in the research study.

All data collected during the online survey will be anonymous and cannot be connected to you in any way, protecting your confidentiality. The survey software used will not record any personal information and will remove any contact associations to further ensure anonymity. Information collected in this project may be shared with other researchers, but anonymity will always be maintained. The anonymized information will be stored safely on a secured university server.

If you have questions about this research study, please contact Taylor S. Martinez, 207 Murchie Science Building, 810-762-3131, tschell@umich.edu or Dr. Charlotte Tang, 207 Murchie Science Building, 810-762-3184, tcharlot@umich.edu.

As part of their review, the University of Michigan Institutional Review Board Health Sciences and Behavioral Sciences has determined that this study is no more than minimal risk and exempt from on-going IRB oversight.

- Yes, I am over the age of 18, self-identify as LGBTQ+ and consent to my responses being used in this research study. (1)
- No, I do not consent (2)

Skip To: End of Survey If An Investigation into How LGBTQ+ Individuals Use Technology to Seek Health Information and Servic... = No, I do not consent

Skip To: End of Block If An Investigation into How LGBTQ+ Individuals Use Technology to Seek Health Information and Servic... = Yes, I am over the age of 18, self identify as LGBTQ+ and consent to my responses being used in this research study.

End of Block: Survey Consent

Start of Block: Demographic Information

Display This Question:

If An Investigation into How LGBTQ+ Individuals Use Technology to Seek Health Information and Servic... = Yes, I am over the age of 18, self identify as LGBTQ+ and consent to my responses being used in this research study.

Q2.1 What is your age?

- 18 - 25 (1)
- 26- 35 (2)
- 36 - 45 (3)
- 46 - 55 (4)
- 56 - 65 (5)
- 66 - 75 (6)
- 76 - 85 (7)
- Over 85 (8)

Q2.2 What is your racial and ethnic identity (check all that apply)?

- White / European American (1)
- African American / Black (2)
- Alaska Native / American Indian (3)
- Asian / Asian American (4)
- Biracial / Multiracial (5)
- Latino / Hispanic (6)
- Middle Eastern / North African (7)
- Native Hawaiian / Pacific Islander (8)
- Other (9) _____

Q2.3 What is your highest level of education?

- 8th grade or less (1)
- Some high school, no diploma or GED (2)
- High school graduate (3)
- GED (4)
- Trade / Technical / Vocational training work (5)
- Some college, no degree (including current undergraduate students) (6)
- Associates degree (7)
- Bachelors degree (8)

- Some graduate work, no graduate degree (including current graduate students) (9)
 - Master's degree (M.A., M.S., M.B.A) (10)
 - Doctoral degree (Ph.D, Ed.D.) (11)
 - Professional degree (M.D., J.D.) (12)
-

Q2.4 What is your current employment status (check all that apply)?

- Employed - Full time (1)
- Employed - Part time (2)
- Self employed (3)
- Unemployed - seeking employment (4)
- Unemployed - not seeking employment (5)
- Unemployed - due to disability (6)
- Student (7)
- Retired (8)
- Homemaker or care giver (9)
- Work under the table (10)
- Illegal work (11)
- Other (12) _____

Q2.5 What is your main form of transportation?

- Your own vehicle (1)
- Rides from family or friends (2)
- Car hire (Taxis, Uber, Lyft) (3)
- Bus (4)
- Subway (5)
- Walk (6)
- Other (7) _____

End of Block: Demographic Information

Start of Block: LGBTQ+ Identity information

Q3.2 Sex identified at birth?

- Male (1)
- Female (2)
- Intersex (3)

Q3.3 What is your current gender identity?

- Agender (1)
 - Bigender (2)
 - Cisgender (3)
 - Gender fluid (4)
 - Gender non-conforming (5)
 - Gender normative (6)
 - Gender queer (7)
 - Nonbinary (8)
 - Queer (9)
 - Third gender (10)
 - Trans (11)
 - Transgender (12)
 - Transsexual (13)
 - Two-spirited (14)
 - Other (15) _____
-

Q3.4 Has your gender identity changed over your lifetime?

Yes (1)

No (2)

Skip To: Q3.6 If Has your gender identity changed over your lifetime? = No

Display This Question:

If Has your gender identity changed over your lifetime? = Yes

Q3.5 Please explain how your gender identity has changed?

Q3.6 What are your pronouns?

- she, her, hers (1)
- he, him, his (2)
- they, them, theirs (3)
- ze, zir (4)
- Other (5) _____

Q3.7 What is your marital status?

- Single, never married (1)
 - Registered domestic partnership (2)
 - Legally recognized civil union (3)
 - Married (4)
 - Divorced (5)
 - Seperated (6)
 - Widow (7)
-

Q3.8 Relationship type (check all that apply)?

- Single (1)
 - Partnered, not living together (2)
 - Partnered, living together (3)
 - Monogamous (4)
 - Polyamorous (5)
 - Casual Only (6)
 - Multiple partners (7)
-

Q3.9 What is your sexual orientation (check all that apply)?

- Heterosexual / Straight (1)
- Gay (2)
- Lesbian (3)
- Bisexual (4)
- Asexual (5)
- Pansexual (6)
- Demisexual (7)
- Same-gender loving (8)
- Queer (9)
- Other (10) _____

Q3.10 Has your sexual orientation changed over your lifetime?

- Yes (1)
- No (2)

Skip To: Q3.12 If Has your sexual orientation changed over your lifetime? = No

Display This Question:

If Has your sexual orientation changed over your lifetime? = Yes

Q3.11 Please explain how your sexual orientation has changed?

Q3.12 As a LGBTQ+ individual, you are (check all that apply)

- Fully out (1)
- Fully in the closet (2)
- Out to friends, closeted to family (3)
- Out in private life but in the closet professionally (4)
- Out to some but closeted to others (5)
- Other (6) _____

End of Block: LGBTQ+ Identity information

Start of Block: Seeking Medical and Health Information

Q4.1 What strategies do you use when seeking health information?

	General health information (1)	LGBTQ+ related health information (2)
Medical professional, facility or organization (1)	<input type="checkbox"/>	<input type="checkbox"/>
Library (2)	<input type="checkbox"/>	<input type="checkbox"/>
LGBTQ+ center or organization (3)	<input type="checkbox"/>	<input type="checkbox"/>
Family and friends (4)	<input type="checkbox"/>	<input type="checkbox"/>
Internet (5)	<input type="checkbox"/>	<input type="checkbox"/>
Other (6)	<input type="checkbox"/>	<input type="checkbox"/>

Q4.2 Have the strategies you normally use to seek health information changed due to the COVID-19 pandemic?

Yes (1)

No (2)

Skip To: Q4.4A If Have the strategies you normally use to seek health information changed due to the COVID-19 pande... = No

Display This Question:

If Have the strategies you normally use to seek health information changed due to the COVID-19 pande... = Yes

Q4.3 Please explain how your strategy for seeking health information has changed since the COVID-19 pandemic.

Skip To: Q4.4A If Condition: Please explain how your str... Is Not Empty. Skip To: Please select all the general health

Skip To: Q4.4A If Condition: Please explain how your str... Is Empty. Skip To: Please select all the general health

Q4.4 Please select all the health topics you have researched online.

- General health information (1)
- LGBTQ+ related health information (2)
- LGBTQ+ friendly health providers (3)
- Sexual health information (4)
- Reproductive health providers (5)
- Sexuality or sexual attraction (6)
- Family planning (7)
- Condoms, contraceptives or other birth control (8)
- Sexually transmitted diseases and infections (9)
- Transitioning (10)
- Mental health providers (11)
- Information related to depression, suicide or anxiety. (12)
- Drug or alcohol abuse (13)
- Domestic violence or abuse (14)
- Sexual assault (15)
- Primary health care providers (16)
- Specialty medical providers (17)

- Health insurance costs (18)
- Health insurance coverage (19)
- Diagnosis from medical professional (20)
- Information to self diagnosis (21)
- Procedures (22)
- Treatments (23)
- Symptoms (24)
- Prescribed medicines and side effects (25)
- Home remedies or cures (26)
- Over the counter medicines (27)
- Medical devices or equipment (28)
- Fitness or exercise (29)
- Diet or nutrition (30)
- COVID-19 (31)
- I don't research health information online (32)
- Other (33) _____

Q4.4A Please select all the medical provider and health insurance topics you have researched online.

Primary health care providers (16)

Specialty medical providers (17)

Health insurance costs (18)

Health insurance coverage (19)

I have not researched medical providers or health insurance related information online
(32)

Other (33) _____

Q4.4B Please select all the general health topics you have researched online.

- General health information (1)
 - Diagnosis from medical professional (20)
 - Information to self diagnosis (21)
 - Procedures (22)
 - Treatments (23)
 - Symptoms (24)
 - Fitness or exercise (29)
 - Diet or nutrition (30)
 - COVID-19 (31)
 - I have not researched general health information online (32)
 - Other (33) _____
-

Q4.4C Please select all the medicine and medical device related information you have researched online.

- Prescribed medicines and side effects (25)
 - Home remedies or cures (26)
 - Over the counter medicines (27)
 - Medical devices or equipment (28)
 - I have not researched medicine and medical device related health information online (32)
 - Other (33) _____
-

Q4.4D Please select all the LGBTQ+ related health topics you have researched online.

- LGBTQ+ related health information (2)
 - LGBTQ+ friendly health providers (3)
 - Sexuality or sexual attraction (6)
 - Transitioning (10)
 - I have not researched LGBTQ+ related health information online (32)
 - Other (33) _____
-

Q4.4E Please select all the mental health topics you have researched online.

- Mental health providers (11)
 - Information related to depression, suicide or anxiety. (12)
 - Drug or alcohol abuse (13)
 - Domestic violence or abuse (14)
 - I have not researched mental health information online. (32)
 - Other (33) _____
-

Q4.4F Please select all the reproductive and sexual health topics you have researched online.

- Sexual health information (4)
 - Reproductive health providers (5)
 - Family planning (7)
 - Condoms, contraceptives or other birth control (8)
 - Sexually transmitted diseases and infections (9)
 - Transitioning (10)
 - Sexual assault (15)
 - I have not researched reproductive and sexual health information online. (32)
 - Other (33) _____
-

Q4.5 When seeking general health information ...

	Very (1)	Somewhat (2)	Neutral (3)	Not very (4)	Not at all (5)	Have not searched (6)
it was difficult to find. (1)	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
sexual health information was difficult to find. (2)	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
the search results were productive. (3)	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
the information found was accurate and helpful. (4)	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q4.6 When seeking LGBTQ+ focused health information ...

	Very (1)	Somewhat (2)	Neutral (3)	Not very (4)	Not at all (5)	Have not searched (6)
general health information was difficult to find. (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
sexual health information was difficult to find. (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Please check the neutral box for this one. (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
the search results were productive. (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
the information found was accurate and helpful. (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q4.7 When seeking mental health information...

	Very (1)	Somewhat (2)	Neutral (3)	Not very (4)	Not at all (5)	Have not searched (6)
it was difficult to find. (1)	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
LGBTQ+ focused information was difficult to find. (2)	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
the search results were productive. (3)	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
the information found was accurate and helpful? (4)	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q4.8 Please describe what health information is easiest for you to find?

Q4.9 Are your health information needs being met with regards to...

	Fully met (1)	Somewhat met (2)	Neutral (3)	Not quite met (4)	Not met at all (5)
General, everyday health (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
LGBTQ+ specific health (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mental health (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sexual health (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family planning (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Specialty care (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Health insurance (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q4.10 Please describe how seeking health and medical information could be made easier for you as a member of the LGBTQ+ community?

End of Block: Seeking Medical and Health Information

Start of Block: General Health Information

Q5.1 What is your current health status?

Poor (1)

Fair (2)

Good (3)

Very good (4)

Excellent (5)

Q5.2 Have you

	In the past 12 months (1)	Ever (2)
Not seen a doctor because you could not afford it? (1)	<input type="checkbox"/>	<input type="checkbox"/>
Stopped using a doctor because you felt you were discriminated against because of your LGBTQ+ identification? (2)	<input type="checkbox"/>	<input type="checkbox"/>
Stopped using a doctor because you felt your LGBTQ+ identity was not acknowledged? (3)	<input type="checkbox"/>	<input type="checkbox"/>
Been denied health care or health information because of your LGBTQ+ identification? (4)	<input type="checkbox"/>	<input type="checkbox"/>
Received medical test or lab results via mobile application or website? (5)	<input type="checkbox"/>	<input type="checkbox"/>
Not taken prescribed medicine because you could not afford to purchase the medication? (6)	<input type="checkbox"/>	<input type="checkbox"/>
Secured your prescribed medication from other sources than a doctor, pharmacy, or other medical facility? (7)	<input type="checkbox"/>	<input type="checkbox"/>
Used a smart watch or other wearable smart device? (8)	<input type="checkbox"/>	<input type="checkbox"/>
Used other non-wearable smart devices (speakers, security cameras, appliances, switches, plugs, lighting, etc)? (9)	<input type="checkbox"/>	<input type="checkbox"/>
None of the above. (10)	<input type="checkbox"/>	<input type="checkbox"/>

Q5.3 Have you had problems getting prescription medicines since the COVID-19 pandemic started?

- Yes (1)
- No (2)
- Does not apply (3)

Display This Question:

If Have you had problems getting prescription medicines since the COVID-19 pandemic started? = Yes

Q5.4 Please explain the challenges you encountered related to getting prescription medication and how you dealt with the challenges.

Q5.5 Have you had to change the method you use to get your prescriptions and medical devices from the pharmacy due to COVID-19 (for example no longer going to the pharmacy but having them delivered)?

- Yes (1)
- No (2)
- Does not apply (3)

Display This Question:

If Have you had to change the method you use to get your prescriptions and medical devices from the... = Yes

Q5.6 Please explain how the method you use to get your prescriptions and medical devices from the pharmacy has changed due to COVID-19.

Q5.7 Please describe any other challenges or barriers you have experienced when seeking health care information.

End of Block: General Health Information

Start of Block: Health Insurance

Q6.1 Are you currently covered by health insurance or coverage plans?

Yes (1)

No (2)

Skip To: Q6.6 If Are you currently covered by health insurance or coverage plans? = No

Q6.2 What is/are the source(s) of your insurance coverage (check all the apply)?

- Through your current or former employer or union (1)
 - Through someone else's current or former employer or union (2)
 - Spouse's plan (3)
 - Parent's plan (4)
 - I or someone else purchased through Healthcare.gov or marketplace ("Obamacare") (5)
 - I or someone else purchased directly from an insurance company (6)
 - Medicare (for people 65 and older, or people with certain disabilities) (7)
 - Medicaid (government-assistance plan for those with low income or a disability) (8)
 - TRICARE or other military health care (9)
 - VA (including those who have ever used or enrolled for VA health care) (10)
 - Indian Health Services (11)
 - Other (12) _____
-

Q6.3 What health care aspects are covered by your health insurance(s)?

	Yes (1)	No (2)	Unsure/ Not Applicable (3)
Need a referral to see specialists (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pre-existing conditions are covered (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
LGBTQ+ related issues considered pre-existing (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
All your LGBTQ+ health needs covered (e.g., IVF, hormone therapy, surrogacy, transitioning or PREP) (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Additional special requirements (referrals, documentation, etc) needed for your LGBTQ+ needs are covered (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Prescriptions are covered (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have mental health coverage (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q6.4 Has your health insurance policy or coverage changed due to the COVID-19 pandemic?

- Yes (1)
- No (2)

Display This Question:

If Has your health insurance policy or coverage changed due to the COVID-19 pandemic? = Yes

Q6.5 Please explain how your health insurance policy or coverage has changed due to the COVID-19 pandemic?

Display This Question:

If Are you currently covered by health insurance or coverage plans? = No

Q6.6 Please explain why you are currently not covered by health insurance.

- Can't afford the price (1)
 - Recently lost insurance (2)
 - Currently seeking insurance (3)
 - Don't feel I need it (4)
 - Other (5) _____
-

Q6.7 Have you lost your health insurance coverage due to the COVID-19 pandemic?

- Yes (1)
 - No (2)
-

Display This Question:

If Have you lost your health insurance coverage due to the COVID-19 pandemic? = Yes

Q6.8 Why was your health insurance coverage lost due to the COVID-19 pandemic?

End of Block: Health Insurance

Start of Block: Mental Health Information

Q7.1 Have you ever researched mental health online to find out more about it?

- Yes (1)
 - No (2)
 - Not applicable (3)
-

Q7.2 For your mental health, do you use... (check all that apply)

- LGBTQ+ specialized mental health provider (1)
 - Mental health apps (2)
 - LGBTQ+ specific mental health apps (3)
 - Meditation apps (4)
 - Mindfulness apps (5)
 - LGBTQ+ related support groups / apps / sites (6)
 - None of the above (7)
-

Q7.3 Prior to COVID-19 pandemic, had you felt (check all that apply)

- Nervous or anxious (1)
 - Restless or fidgety (2)
 - Hopeless (3)
 - Worthless (4)
 - Everything was an effort (5)
 - None of these (6)
-

Q7.4 Has your mental health suffered during the COVID-19 pandemic?

- A great deal (1)
 - A lot (2)
 - A moderate amount (3)
 - A little (4)
 - None at all (5)
-

Q7.5 Have you sought mental health care to help you cope with the COVID-19 pandemic?

- Yes (1)
 - No (2)
 - Prefer not to answer (3)
-

Display This Question:

If Have you sought mental health care to help you cope with the COVID-19 pandemic? = Yes

Q7.6 Is this the first time you have ever sought mental health care?

- Yes (1)
 - No (2)
 - Prefer not to answer (3)
-

Q7.7 Do you have a mental health provider?

- Yes (1)
- No (2)

Skip To: End of Block If Do you have a mental health provider? = No

Q7.8 Do you see a...(check all that apply)?

- Peer-counselor (1)
 - Counselor (2)
 - Certified Therapist (3)
 - Clinical Social Worker (4)
 - Psychologist (5)
 - Psychiatrist (6)
 - Other (7) _____
-

Q7.9 How did you find your mental health provider (check all that apply)?

- Family and friends (1)
- Medical professional or organization (2)
- LGBTQ+ organization (3)
- Online Search (4)
- Advertisement (5)
- Health insurance network (6)
- Other (7)

Q7.10 Do you feel your mental health provider and their staff...

	Very much (1)	Somewhat (2)	Neutral (3)	Very little (4)	Not at all (5)
Treat you with respect? (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Acknowledge your LGBTQ+ identity? (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Address your medical needs as a LGBTQ+ individual? (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sensitive to your medical needs as a LGBTQ+ individual? (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Knowledgeable about your medical needs as a LGBTQ+ individual? (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Are you satisfied with the care you receive? (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q7.11 Did your mental health care provider ask about your...

	Yes (1)	No (2)	Unsure/ Can't remember (3)
Preferred name or nickname? (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Preferred pronouns? (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sexual orientation? (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Gender identity? (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q7.12 Prior to the COVID-19 pandemic, how did you interact with your mental health professional(s) (check all that apply)?

- In-person (1)
 - Online (2)
 - Email (3)
 - Text / Messaging (4)
 - Mobile app (5)
 - Video chat (6)
 - I did not have one prior to COVID-19 (7)
 - Other (8) _____
-

Q7.13 Has your mental health care provider canceled or postponed appointments due to the COVID-19 pandemic?

- Yes (1)
 - No (2)
 - Does not apply (3)
-

Q7.14 Did you choose to cancel or postpone any mental health appointments due to the COVID-19 pandemic?

- Yes (1)
 - No (2)
 - Does not apply (3)
-

Q7.15 Since COVID-19, have the platforms you use for your mental health services changed (for example changing from in-person to audio, video or text)?

- Yes (1)
- No (2)
- Does not apply (3)

Skip To: Q7.18 If Since COVID-19 Have the platforms you use for your medical appointments changed since the COVID-19 vi = No

Skip To: Q7.18 If Since COVID-19 Have the platforms you use for your medical appointments changed since the COVID-19 vi = Does not apply

Q7.16 How satisfied were you with the new format of mental health care you received?

- Extremely satisfied (1)
 - Somewhat satisfied (2)
 - Neither satisfied nor dissatisfied (3)
 - Somewhat dissatisfied (4)
 - Extremely dissatisfied (5)
-

Q7.17 Please describe how the mental health care format changed due to COVID-19 and your experience with this new format of mental health care.

Q7.18 How satisfied were you with your mental health professional's overall response to the COVID-19 pandemic?

- Extremely satisfied (1)
- Somewhat satisfied (2)
- Neither satisfied nor dissatisfied (3)
- Somewhat dissatisfied (4)
- Extremely dissatisfied (5)

Q7.19 What suggestions, if any, would you make to your mental health professional to improve their response to COVID-19 and allow for a more seamless mental health care process?

End of Block: Mental Health Information

Start of Block: Primary Health Provider

Q8.1 Do you have a primary care provider?

- Yes (1)
- No (2)

Skip To: Q8.14 If Do you have a primary care provider? = No

Display This Question:

If Do you have a primary care provider? = Yes



Q8.2 For how many years have you received care from your current primary care provider?

Q8.3 How did you find your primary care provider (check all that apply)?

- Family and friends (1)
- Medical professional or organization (2)
- LGBTQ+ organization (3)
- Online Search (4)
- Advertisement (5)
- Health insurance network (6)
- Other (7) _____

Q8.4 Do you feel your primary care provider and their staff...

	Very much (1)	Somewhat (2)	Neutral (3)	Very little (4)	Not at all (5)
Treat you with respect? (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Acknowledge your LGBTQ+ identity? (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Address your medical needs as a LGBTQ+ individual? (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sensitive to your medical needs as a LGBTQ+ individual? (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Knowledgeable about your medical needs as a LGBTQ+ individual? (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Are you satisfied with the care you receive? (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q8.5 Did your primary care provider ask about your...

	Yes (1)	No (2)	Unsure/Can't Remember (3)
Preferred name or nickname? (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pronouns? (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sexual orientation? (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Gender identity? (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q8.6 Prior to the COVID-19 pandemic, how did you typically communicate with your primary care provider, including scheduling appointments, getting results, virtual appointments and payments (check all that apply)?

- Postal mail (1)
 - Phone (2)
 - Email (3)
 - Text Message (4)
 - Messaging via patient portal (5)
 - Mobile application (6)
 - Website (7)
 - Social media (8)
 - Other (9) _____
-

Q8.7 Has your primary health care provider canceled or postponed medical appointments or procedures due to the COVID-19 pandemic?

- Yes (1)
 - No (2)
 - Does not apply (3)
-

Q8.8 Have you chosen to cancel or postpone any medical appointments or procedures due to the COVID-19 pandemic?

- Yes (1)
 - No (2)
 - Does not apply (3)
-

Q8.9 Since the COVID-19 pandemic began, have the platforms you use for your medical appointments changed (for example changing from in-person to audio, video or text)?

- Yes (1)
- No (2)
- Does not apply (3)

Skip To: Q8.12 If Since the COVID-19 pandemic began, have the platforms you use for your medical appointments chang... = No

Skip To: Q8.12 If Since the COVID-19 pandemic began, have the platforms you use for your medical appointments chang... = Does not apply

Display This Question:

If Since the COVID-19 pandemic began, have the platforms you use for your medical appointments chang... = Yes

Q8.10 How satisfied were you with the new format of medical care you received?

- Extremely satisfied (1)
- Somewhat satisfied (2)
- Neither satisfied nor dissatisfied (3)
- Somewhat dissatisfied (4)
- Extremely dissatisfied (5)

Q8.11 Please describe how the medical care format changed and your experience with this new format of medical care (ease of use, satisfaction level with service, challenges).

Q8.12 How satisfied were you with your primary care professional's response to COVID-19?

- Extremely satisfied (1)
- Somewhat satisfied (2)
- Neither satisfied nor dissatisfied (3)
- Somewhat dissatisfied (4)
- Extremely dissatisfied (5)

Q8.13 What suggestions, if any, would you make to your primary health care professional to improve their response to COVID-19 and allow for a more seamlessly care process?

Display This Question:

If Do you have a primary care provider? = No

Q8.14 Please explain why you currently do not have a primary care provider.

End of Block: Primary Health Provider

Start of Block: Voice Assistants

Q9.0 Do you use a voice assistant like Siri, Alexa, Google Assistant, Bixby, Cortana, or S voice?

- Yes (1)
- No (2)

Skip To: Q9.0A If Do you use a voice assistant like Siri, Alexa, Google Assistant, Bixby, Cortana, or S voice? = No

Skip To: Q9.2 If Do you use a voice assistant like Siri, Alexa, Google Assistant, Bixby, Cortana, or S voice? = Yes

Display This Question:

If Do you use a voice assistant like Siri, Alexa, Google Assistant, Bixby, Cortana, or S voice? = No

Q9.0A Please explain why do you not use a voice assistant like Siri, Alexa, Google Assistant, Bixby, Cortana, or S voice.

Skip To: End of Block If Condition: Please explain why do you n... Is Displayed. Skip To: End of Block.

Display This Question:
If Do you use a voice assistant like Siri, Alexa, Google Assistant, Bixby, Cortana, or S voice? = Yes

Q9.2 Which voice assistant(s) do you use (check all that apply)?

- Alexa (1)
- Siri (2)
- Google Assistant (3)
- Bixby (4)
- Cortana (5)
- S voice (6)
- Other (7) _____

Q9.1 Do you use your voice assistant (Siri, Alexa, Google Assistant, Bixby, Cortana, S voice, etc.) for your health information and healthcare needs?

- Yes (1)
- No (2)

Skip To: Q9.5 If Do you use your voice assistant (Siri, Alexa, Google Assistant, Bixby, Cortana, S voice, etc.) fo... = No

Display This Question:
If Do you use your voice assistant (Siri, Alexa, Google Assistant, Bixby, Cortana, S voice, etc.) fo... = Yes

Q9.3 How do you use the voice assistance in relation to your health and healthcare (check all that apply)?

- Research health information (1)
- Schedule medical appointments and tests (2)
- Pay medical related bills and health insurance online (3)
- Get lab and test results (4)
- Track health information from wearable devices (5)
- Set health related reminders, tasks and calendar events (6)
- Refill prescriptions (7)
- Order medical equipment (8)
- Other (9) _____

Q9.4 Please describe any challenges you have experienced when using a voice assistant to seek health information.

Display This Question:
If Do you use your voice assistant (Siri, Alexa, Google Assistant, Bixby, Cortana, S voice, etc.) fo... = No

Q9.5 If you use a voice assistant but do not use it for healthcare and health related activities, can you explain why you do not use it for health-related activities?

End of Block: Voice Assistants

Start of Block: Interview promo

Q10.1 Thank you for participating in this survey.

If you are interested in also participating in a telephone interview about this topic please contact Taylor S Martinez at tshell@umich.edu We would love to hear more about your experiences. The phone interview will take approximately 25 minutes to complete and can be scheduled to fit your time constraints. To read more about the interview process please visit go.umflint.edu/LGBTQTechInterviewConsent

End of Block: Interview promo

C.2 Survey Recruitment Flyer

This was the flyer used to recruit participants for the survey and uncompensated interviews.



COLLEGE OF ARTS & SCIENCES COMPUTER SCIENCE

If you self-identify as LGBTQ+ and are over the age of 18, we are looking for your input...

We are researchers at the University of Michigan – Flint’s Computer Science Department and we would like to invite you to participate in a study to investigate how technologies are used by LGBTQ+ individuals when seeking health information and services. Our goal is to improve access to accurate, relevant health information and health care for the LGBTQ+ community.

If you would like to participate, there are 2 ways you can do so...

- A survey. You can take our online survey from the comfort and privacy of your own home. The survey will take approximately 20 minutes of your time to complete and can be found at go.umflint.edu/LGBTQTechSurvey

OR

- An interview. You can participate in a confidential phone interview with one of our researchers. The phone interview will take approximately 25 minutes to complete and can be scheduled to fit your time constraints by emailing tschell@umich.edu

We respect your privacy, so any information collected will be kept completely confidential. Find the information and consent forms here

Survey go.umflint.edu/LGBTQTechSurveyConsent

Interview go.umflint.edu/LGBTQTechInterviewConsent

We look forward to hearing about your health information and care seeking experiences.

C.3 Survey Recruitment Email

Good day,

I am writing to you today as a LGBTQ+ ally and proud mother of a pansexual genderfluid young adult. I am attempting to use my skills to help enact inclusivity and equality for the LGBTQ+ community but I am hoping I could get your help to do so.

A way I thought I could be of service, as a graduate student seeking her master's in computer science, is by studying if technology is serving the LGBTQ+ community needs as it relates to health information seeking and health care services. If it is not, how can we improve or design new technology so that it does meet the LGBTQ+ communities' needs. I am conducting both an online survey and a separate interview (people can participate in either or both) to find out LGBTQ+ individuals' experiences on the topic. More details can be found in the attached document.

I want this study to truly be able to make a difference for the LGBTQ+ community but for that to happen I need as many people, who identify as LGBTQ+, as possible to participate and have a voice in the survey and/or interview. I am hoping you would be so gracious to help by either participating yourself or sharing the information about the research study on your available platforms. It would have a huge impact on the reach of the study and greatly improve its ability to identify issues that need to be addressed.

Together we can make the world an inclusive space. I hope this study can be a step to making that happen.

Please complete the survey here: go.umflint.edu/LGBTQTechSurvey

Thank you so much for taking the time to read this.

Sincerely,

Taylor S. Martinez

she/ her /hers

MS student

Computer Science Department

University of Michigan - Flint

tschell@umich.edu

Faculty advisor: Dr. Charlotte Tang

APPENDIX D: IRB APPROVAL

D.1 IRB Exemption and Approval



Health Sciences and Behavioral Sciences Institutional Review Board (IRB-HSBS) • 2800 Plymouth Rd., Building 520, Room 1170, Ann Arbor, MI
48109-2800 • phone (734) 936-
0933 • fax (734) 998-9171 • irbhsbs@umich.edu

To:

Taylor
Martine

Z

From:

Thad Polk

Cc:

Taylor Martinez
Charlotte Tang

Subject: Notice of Exemption for [HUM00188636]

SUBMISSION INFORMATION:

Title: An Investigation into How LGBTQ+ Individuals Use Technology to Seek Health Information and Services.

Full Study Title (if applicable):

Study eResearch ID: [HUM00188636](#)

Date of this Notification from IRB: 11/6/2020

Date of IRB Exempt Determination: 11/6/2020

UM Federalwide Assurance: FWA00004969 (For the current FWA expiration date, please visit the [UM HRPP Webpage](#))

OHRP IRB Registration Number(s): IRB00000246

IRB EXEMPTION STATUS:

The IRB HSBS has reviewed the study referenced above and determined that, as currently described, it is exempt from ongoing IRB review, per the following federal exemption category:

EXEMPTION 2(i) and/or 2(ii) at 45 CFR 46.104(d):

Research that only includes interactions involving educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior (including visual or auditory recording) **if at least one of the following criteria is met:**

(i) The information obtained is recorded by the investigator in such a manner that **the identity of the human subjects cannot readily be ascertained**, directly or through identifiers linked to the subjects;

(ii) Any disclosure of the **human subjects' responses** outside the research **would not reasonably place the subjects at risk** of criminal or civil liability or be damaging to the subjects' financial standing, employability, educational advancement, or reputation

Note that the study is considered exempt as long as any changes to the use of human subjects (including their data) remain within the scope of the exemption category above. Any proposed changes that may exceed the scope of this category, or the approval conditions of any other non-IRB reviewing committees, must be submitted as an amendment through eResearch.

<https://errm.umich.edu/ERRM/sd/Doc/0/OVUAKSH0AC8UNDK149HQMLIG00/fromString.html>
<https://errm.umich.edu/ERRM/sd/Doc/0/OVUAKSH0AC8UNDK149HQMLIG00/fromString.html>

1/2 3/6/22, 10:56 AM

Although an exemption determination eliminates the need for ongoing IRB review and approval, you still have an obligation to understand and abide by generally accepted principles of responsible and ethical conduct of research. Examples of these principles can be found in the Belmont Report as well as in guidance from professional societies and scientific organizations.

SUBMITTING AMENDMENTS VIA eRESEARCH:

You can access the online forms for amendments in the eResearch workspace for this exempt study, referenced above.

ACCESSING EXEMPT STUDIES IN eRESEARCH:

Click the "Exempt and Not Regulated" tab in your eResearch home workspace to access this exempt study.



Thad Polk
Chair, IRB HSBS

D.2 IRB Brief Protocol

AMENDED Brief Protocol for #HUM001886

1. SUBJECT POPULATION

We will be seeking between 50 and 300 self-identifying LGBTQ+ individuals who are over the age of 18 and are willing to take an online survey investigating their technology use and behavior in relation to health information seeking and health services.

We will also be seeking 10 to 30 self-identifying LGBTQ+ individuals who are over the age of 18 to participate in phone interviews, that will be audio recorded, investigating their technology use in relation to health information seeking and health services.

AMENDED MAY 2021 (Ame00112139)

We will also be seeking 10 to 30 medical providers, over the age of 18, who currently provide medical care to the general population to participate in phone or Zoom interviews, that will be audio recorded, investigating how they approach sex, gender, sexual orientation and pronouns with their patients and their professional knowledge level and confidence to navigate these topics and other LGBTQ+ health topics.

We will also be seeking 10 to 30 medical educators, over the age of 18, who work at the university level that educate the next generation of medical professionals to participate in interviews, that will be audio recorded, investigating how they educate their students to approach LGBTQ+ health and inclusivity, their school's requirements for students and their own professional knowledge level and confidence to navigate educating these topics and other LGBTQ+ health topics.

2. SUBJECT RECRUITMENT

Researchers will recruit all participants through social media posts, emails, and word of mouth. The attached "flyer" will be posted on several social media sites including Instagram, Facebook, and Twitter seeking respondents. It will also be sent via the university's email system and via the university's Center for Gender and Sexuality.

AMENDED MAY 2021 (Ame00112139)

Updated LGBTQ+ participation flyer to reflect the \$20 gift card payment to interviewees.

A separate attached flyer will be used to recruit medical provider and educator interviewees and will be circulated in the same ways as listed above.

3. RESEARCH LOCATION

The interviews, due to the pandemic, will be conducted over the telephone or via Zoom. The researchers will conduct the interviews from a remote location away from campus and from the University of Michigan -Flint campus itself as permitted. Cyberspace will be the location of the survey as it will be administered online with no actual contact between researcher and participant. Both data sets will be analyzed at remote locations and on campus.

4. RESEARCH PROCEDURES

The online surveys will be conducted anonymously online using Qualtrics software. There will be no contact between survey takers and researchers. The first question of the survey will provide an information sheet about the research study and allow the participant to participate by selecting "I agree" or "I do not agree" to consent to participate in this study. Qualtrics software will not record any personal information about the survey taker and will remove contact associations from the data collected to ensure anonymity of the participant. All data collected will then be safely stored on a secured cloud-based university storage drive.

Interviews will be conducted over the phone and will be audio recorded. Participant names will not be collected or used during research. Participants' identity will be protected by masking them with an alias from initial contact forward, in all data, publications, and presentations. Only the investigators of this study will have access to the audio recordings. The audio recordings will be transcribed into a text document for analysis with participants identified by the aliases only, permanently de-identifying the responses. The audio-recordings will be safely stored on a secured cloud-based university storage drive for three years after the study and then will be permanently erased. The de-identified transcriptions of the audio-recordings will be stored indefinitely. Any data collected will be safely stored on a secured cloud-based university storage drive (the university's Google drive).

AMENDED MAY 2021 (Ame00112139)

Interviews with LGBTQ+ individuals will be conducted and de-identified as explained above.

Interviews with medical providers and medical educators will be conducted in the same fashion except their name will be known but their identity also will be protected by masking them with an alias from initial contact forward, in all data, publications, and presentations in the same manner as the LGBTQ+ individuals' identities will be protected.

5. COMPENSATION

There is no financial incentive or compensation for participation in the interview.

AMENDED MAY 2021 (Ame00112139)

Surveys completed by LGBTQ+ individuals will receive no financial incentive or compensation for participation in the survey.

LGBTQ+ interviewees will be compensated \$20 each, from a \$500 2021 University of Michigan - Flint CAS Opportunity Fund Grant that Taylor Martinez received for the purpose of paying participants of the LGBTQ+ interview for their time.

Interviews with medical providers and medical educators will receive no financial incentive or compensation for participation in the interview.

6. DATA SECURITY AND STORAGE PLAN

All data collected from this research project will be safely stored on a secured cloud-based university storage drive (the university's Google drive). The anonymous data from the online surveys and the de-identified text data transcribed from the interview audio voice recordings will be stored indefinitely on this drive. The audio voice recordings of the interviewees will be stored on a secured cloud-based university storage drive for 3 years after the study's completion, after which time they will be destroyed.

AMENDED MAY 2021 (Ame00112139)

Interviews with medical professionals and medical educators will also be transcribed and stored indefinitely on the same university drive in the same manner as the other data.

APPENDIX E: CO-AUTHOR PERMISSION

I, Charlotte Tang, give Taylor Schell Martinez permission to use co-authored work from our papers, *Design Implications for Health Technology to Support LGBTQ+ Community: a literature review* and *The impact of COVID-19 on LGBTQIA+ individuals' technology use to seek health information and services* in Chapter 2 and Chapter 4 of her thesis.

Sincerely,



Charlotte Tang

__May 11, 2022__

Date