

Needs Assessment of Older LGBT+ Adults Living with HIV in Puerto Rico

Waves Ahead Corp

JSI Research & Training Institute, Inc.

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Authors' contribution statement

Dr Wilfred Labiosa (Waves Ahead, Inc, SAGE PR) identified the need for this research and procured funding, provided oversight and leadership responsibility for all research activities planning and execution. Funding was provided by AIDS United, SAGE Puerto Rico, SAGE's HIV & Aging Policy Action Coalition, and Gilead Sciences, Inc. Gilead Sciences had no input in the development or content of these materials. Dr. Rodolfo R. Vega (JSI) developed the research design, constructed sampling frame, conducted the investigation, analyze the data, and wrote the report. Staff members of Waves Ahead, Inc, (among them: Kiaranel Castro Lebrón, Kimberly Vázquez Arciliares, Seil Roman) recruited participants, collected data and conducted interviews. Special gratitude to you, the many community members who provided feedback of the tool and assisted in the outreach activities.

Alexandra M. Bonnet, MSW (Alexia Consulting, LLC) translated from English to Spanish the survey instruments, compiled and pilot tested the survey, ensured survey validation through cognitive interviewing, contributed to; data collection, data analysis, data visualization, and report writing as well as design in all the different formats developed. Neryna Cuadrado (Cuadrado Art) was the graphic artist for the reports. Mihali Imre (JSI) managed software development and the survey data. Charlotte Algers was the statistician of this study.

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EXECUTIVE SUMMARY

Importance

Policymakers, researchers, advocates, and service providers in Puerto Rico (and the United States more generally) lack research-informed knowledge about the health needs of older LGBT+ adults living with HIV. This Community Needs Assessment was implemented as an initial step to remedy that situation.

Methods

Information on the lived experience of 277 Latinx people, aged 50 or more, living with HIV in Puerto Rico, and proud members of the LGBT+ community was collected through surveys (n=264) and in-depth interviews (n=13).

Results

The typical respondent was a person who knows how to navigate the healthcare system, has developed coping mechanisms to deal with stigma and homophobia, and serves as a champion and fierce advocate of younger LGBT+ folks. Unlike their counterparts in the mainland (older adult and elderly LGBT+ Latinos living with HIV), they are highly educated (graduates and postgraduates); do not experience service barriers due to lack of health insurance, language impediments, or blatant discrimination; do not report a feeling of otherness; and have not regularly experienced encounters with providers lacking in cultural humility. Despite these strengths, a painting emerges from the data that shows people in distress, which is manifested in depression, anxiety, and social isolation. This picture, however, needs to be understood within the frame of the respondents' life context and experiences. A significant portion feel housing and food insecurity, are in need of medical and mental health care, and are not able to obtain complementary and alternative services. Despite their education, they cannot escape poverty. They feel lonely and isolated, lacking a partner/spouse and have no children. The testimonies collected highlight the many circumstances in which they suffer financial hardships from either losing a home to earthquakes/hurricanes or losing their employment or business to Covid-19. Some are still taking care of their aging parents. As all the people living in the island, they have also experienced numerous traumatic events (hurricanes, earthquakes, epidemics, economic collapse).

Recommendations

What can be done to promote the wellbeing of older LGBT+ adults in Puerto Rico living with HIV? First, policymakers should recognize that, for the most part, they obtain their services in a system of care that was designed for the cis-gender heterosexual population. Through their advocacy, assertiveness, and persistence, the respondents have been able to nudge the system to align services delivery in a manner that supports and satisfies their needs. However, these efforts have not been broadly successful. Some respondents still report experiencing HIV, gender, and age discrimination. Second, the strengths of this population should be recognized, celebrated, and activated. Previously, we alluded to some of those strengths (resiliency, assertiveness, and high levels of education). There is a rich intellectual capital within this community. About 27.5% have completed a bachelor's degree, 22% a master's degree and 6% a doctorate degree. Third, there is a need to increase accessibility to all existing services. We encourage a creative and flexible conceptualization of "accessibility." Thus, we encourage policymakers and service providers to consider strengthening the use of social media and mobile services; modifying existing services to address the needs of older LGBT+; involving people with lived experience in service delivery, diversity, equity, and inclusion audits; and other creative solutions "outside of the box," all while using science-based interventions to improve those services that are already in place. Community members' anxiety and distress caused by housing and food insecurity can be mitigated if they are made aware of resources and opportunities to deal with such challenges. Fourth, while most of the participants were digitally literate, they wanted more training and capacity development services in the use of technology. Fifth, the participants reflect a diverse segment of the LGBT+ community, a diverse segment of the LGBT+ community, all elderly and in constant change as time goes by, veterans of living with HIV, and trying to live to their full potential. Public servants, elected officials, public health advocates, providers, and community members-at-large should read these findings as a window to a community that is searching for equity and equality in healthcare, in their community, and in Puerto Rico as whole. Listen, learn, and advocate!

Limitations

First, the data was collected during the COVID-19 epidemic, and it is difficult to ascertain whether the distress documented in the findings is due to COVID-19 or to already existing

causes. Data was collected between late April and June 2021. Second, we referred to the LGBT+ community as a whole. However, between and within the Lesbian, Gay, Bisexual and Transgender community and the myriad sexual orientations denoted by the “+” symbol, there are unique needs, differences, strengths, and worldviews. Due to budgetary limitations, these issues were not attended in this study. Third, the sample was recruited through social media platforms like Facebook and Twitter, meaning that the participants were those that already knew how to access social media. Although some surveys were collected in person, the COVID-19 situation in Puerto Rico at the time impeded us from continuing in this format; hence, we changed all activities to become web based. Fifth, the sample was a non-probability sample, thus the findings are not generalizable to the general population. Finally, this cohort represents “very young older adults”; that is, participants as young as 50-years of age. As such, they did not express the need for assistance in performing activities of daily living typically reported by their old or very old counterparts.

INTRODUCTION

Waves Ahead Corp., in collaboration with SAGE, contracted JSI Research & Training Institute, Inc. (JSI) to conduct a health needs assessment during the Spring and Summer of 2021 of LGBT+ adults aged 50 and above living in Puerto Rico. This report was commissioned by Waves Ahead, Corp. and SAGE PR, a national affiliate of SAGE USA, based in San Juan Puerto Rico. SAGE is the largest and oldest organization in the United States dedicated to improving the lives of older LGBT+ people. It was founded in 1978 and is headquartered in New York City. They offer supportive services and consumer resources to older LGBT+ people and their caregivers. JSI is a health care research and consulting organization based in Boston, MA. JSI was also founded in 1978, the same year as SAGE. Since then, it has grown to a staff of more than 400 with expertise in public health, clinical care, research methods, health policy/reform, health assessment and planning, workforce development, clinical quality, management operations, and information systems.

Waves Ahead, Corp., aims to create a body of evidence to inform future policies, community actions, and research activities to address the health inequities experienced by LGBTTQ+ over 50 living with HIV in Puerto Rico. Specifically, Waves Ahead wants to document needs in the areas of housing, mental health, health care, and technology. It's worth noting that the needs assessment was carried out in the middle of the COVID-19 pandemic. The measures put in place by the federal government and the government of Puerto Rico to mitigate the impact of the epidemic curtailed our recruitment efforts. Questions about COVID-19 were also added to the needs assessment.

Overview

This report first presents an epidemiological profile of the HIV epidemic in the Island of Puerto Rico. It is followed by a demographic profile of the older population in Puerto Rico and an outline of the needs confronted by older LGBT+ adults. It should be noted that the United Nations regards those aged 60 and above as “older adults,” but the age of inclusion has been defined as early as 50 in some studies¹. Waves Ahead is cognizant that the LGBT+ population

¹ Sabharwal, S., Wilson, H., Reilly, P., & Gupte, C. M. (2015). Heterogeneity of the definition of elderly age in current orthopaedic research. *SpringerPlus*, 4, 516. <https://doi.org/10.1186/s40064-015-1307-x>

disconnects with the health care system as they age.² Thus, another motivation for this needs assessment was to identify early factors that might accelerate this health services disconnect in older adulthood.

The report continues with a profile of the HIV epidemic in the Island and the existing health service gaps identified by the Puerto Rico Department of Health in the Integrated HIV Surveillance, Prevention and Care Plan from 2017-2021 (Integrated Plan). This plan is mandated by two agencies of the United States Department of Human Services: HRSA/HAP and the CDC, and it integrates both the prevention and treatment plans of the Puerto Rico Health Department for a period of four years. It includes as a foundation a health needs assessments conducted with services providers and those affected and infected by HIV. Afterwards, the report continues with the Methods, Results, Discussion, and Conclusion sections.

Demographic profile of older adults in Puerto Rico³

As of May 31, 2021, more than 49,923 people have been diagnosed with the HIV infection in Puerto Rico. Of those, 18,892 are living with HIV. The island ranked 10th on the list of American states/territories with the highest number of reported AIDS cases. In 2013, men having sex with men (MSM) without a condom became the principal mode of transmission of HIV surpassing injection drug use. The rate of HIV diagnosis is on average 12 times greater in men between ages 20 and 29 years old, and five times greater in men 60 years old and older. According to an inventory of HIV service providers conducted in 2014 by the Puerto Rico Health Department, there are over 100 organizations in Puerto Rico with 211 centers that provide services related to HIV and STIs, as illustrated on the map below.

² Burton, C. W., Lee, J. A., Waalen, A., & Gibbs, L. M. (2020). "Things are different now but": Older LGBT adults' experiences and unmet needs in health care. *Journal of Transcultural Nursing*, 31(5), 492-501

³ All the data presented in this section was obtained from the Puerto Rico HIV Integrated Plan 2017-2021. <http://10.1.19.102/dataset/38864e0c-8407-46c0-88ed-b7f4d3d22108/resource/31e16d16-24e1-47a7-a3b7-79b567bbaff3/download/puerto-rico-hiv-integrated-plan-2017-2021.pdf>. Accessed July 11.2021

Health needs of older LGBT+ adults

A literature review of aging and HIV conducted by the Williams Institute⁴ revealed that older LGBT+ adults living with HIV are more likely than heterosexual cis-gender adults not living with HIV to:

- face barriers to accessing health care and social support
- avoid or delay health care, or conceal their sexual and gender identity from health providers and social service professionals for fear of discrimination due to their sexual orientation and gender identity
- have fewer options for informal care
- be single or living alone and to be less likely to have children to care for them
- experience lifetime disparities in earnings, employment, and opportunities to build savings
- have worse mental and physical health
- have higher rates of disease and physical disability

Identified needs of older adults in Puerto Rico

This section reviews the HIV epidemiological profile in Puerto Rico and the identified needs of older adults, as documented in the Integrated HIV Surveillance, Prevention and Care Plan for Puerto Rico, 2017-2021. Every four years, the Centers for Diseases Control and the Health Resources Service Administration HIV AIDS Bureau (HRSA/HAB) mandates that all states file an HIV prevention and treatment plan. This plan guides the funding and delivery of all HIV prevention, care, and treatment services on the island. The 2017-2021 HIV Integrated Plan⁵, developed by the SJU/PR Health Department, was constituted in collaboration with people living with HIV and community-based organizations. It identified the following needs specific to older adults:

⁴ <https://williamsinstitute.law.ucla.edu/publications/lgbt-aging/>, Accessed July 11, 2021

⁵ Ibid

- Education about safer sex practices, correct use of condoms, and other methods of protection
- An increase HIV/ITS testing
- Improved transportation services
- Access to medical, nursing and laboratory services
- Access to medications
- Access to counseling services
- Access to case management services

METHODS

All research tasks have been conducted in close collaboration with SAGE PR and its stakeholders. The research team launched an initial kick off meeting during the month of March 2021 in order to agree upon the content of the survey instruments, translation, responsibilities, and deliverables.

Development of survey instruments

The JSI team selected items commonly used in HIV needs assessments, mandated, and approved by Ryan White, and available online;⁶ surveys used by JSI in prior assessments; and items obtained from the HRSA TARGET Center and from the AETC item bank.⁷ Items related to the needs of the elderly were derived from the national elderly survey, and from those suggested by SAGE PR stakeholders.

Language and culture

We recognize that there are marked cultural and linguistic differences between the population for which many of the selected items were developed and the intended population. We also acknowledge existing intra-group racial, educational and socioeconomic differences between Puerto Ricans who lived most of their lives in the San Juan Metropolitan Area and those who live outside of the Metro area.

Although the influence of those differences cannot be eradicated, we have mitigated, to the best of our ability, their impact by employing the following strategies:

- Identified items that have been implemented with Spanish-speaking population
- Gauged the face-validity of the selected items
- Consulted with SAGE PR and its stakeholders to conduct an expert review panel of selected items
- Assessed the readability level of the items
- Conducted a cognitive interview item review with 5 members of the survey population

⁶ aidsetc.org/sites/default/files/resources_files/NECQuestion%20Bank

⁷ <https://agid.acl.gov/DataFiles/Documents/NPS/SurveyInstrument2003.pdf>

- Examined item-response patterns
- Included strategies and suggestions from SAGE PR stakeholders
- Pilot test survey

Sample selection and distribution

Survey participants were recruited through a purposive non-randomized sample comprised of Puerto Rican self-identified LBGTQ+ individuals over 50 years of age living with HIV. We worked closely with SAGE PR to develop a recruiting strategy that included three strategies: broad dissemination through social media; surveys distributed at points of care, and surveys distributed through community-based organizations. The survey was available both in electronic form and in paper format. For the purposes of this assessment, participants were considered as subject matter experts because of their lived experiences.

Sample size

According to the 2017-2021 Puerto Rico HIV Integrated Plan, 6,209 people aged 50+ are living with HIV/AIDS in Puerto Rico. The Williams Institute estimates that LGBT+ population is 4.5% of this total population.⁸ Thus we estimate that there are about 1,242 people aged 50+ that are members of the LGBT+ community living with HIV/AIDS in Puerto Rico. We collected and analyzed 264 eligible surveys. That means that we collected data on 21% of the population. The margin of error for our survey (using a finite population correction) therefore is 5.36%.⁹ The rule of thumb with survey design is to target a margin of error of 5%, indicating our survey is reliable representation of this population.¹⁰

⁸ <https://williamsinstitute.law.ucla.edu/publications/adult-lgbt-pop-us/>

⁹ We used this online calculator <https://goodcalculators.com/margin-of-error-calculator>

¹⁰ van Belle, G. (2011). Statistical Rules of Thumb. Germany: Wiley.

Survey development and programming

This health assessment included three data collection modalities: a web-based survey, a paper survey, and in-depth qualitative interviews. All data collection was conducted in Spanish.

Web-based survey

The online survey was administered through Alchemer, an advanced and highly capable online software survey tool. It has a simple and endlessly customizable interface that allows organizations to create unique and accessible surveys and forms. Alchemer has multiple layers of data encryption to ensure respondent confidentiality and secure data transfer. The URLs generated for online surveys are “https” links, which use Secure Socket Layer to transport data safely between client and survey using an encryption algorithm. These links ensure that all data passed between the web server and browsers remain private and integral

Paper survey

We also developed print paper versions of the survey. Paper surveys were created using the TeleForm scanning software that allows for printed forms to be processed electronically. TeleForm is a data capture system designed to reduce data entry associated with paper-based forms. It reads handprint, machine print, optical marks, barcodes and signatures, and has built in functions that flag ambiguous marks and alert a human operator to resolve the ambiguities. Completed survey forms were scanned and verified by staff trained in processing surveys electronically, and data was exported from TeleForm into SPSS, a statistical software package. The structure and format of this data was triangulated with that of the web-based survey, to ensure that data could be readily integrated between different modes of administration.

In-depth qualitative interviews

We conducted 13 in depth interviews with members of the study population. Informed consents were obtained from each participant. The interviews were professionally transcribed, coded and analyzed using a thematic qualitative data analytic approach.

IRB approval

The JSI Institutional Review Board (OHRP IRB00009069 John Snow, Inc.) determined that this study is exempt from human subjects' oversight. The basis of this exemption is CFR 46.101 (b) (2), which covers survey activities without identifiers or sensitive questions that could result in harm; no participants in the study was younger than 18 years of age.

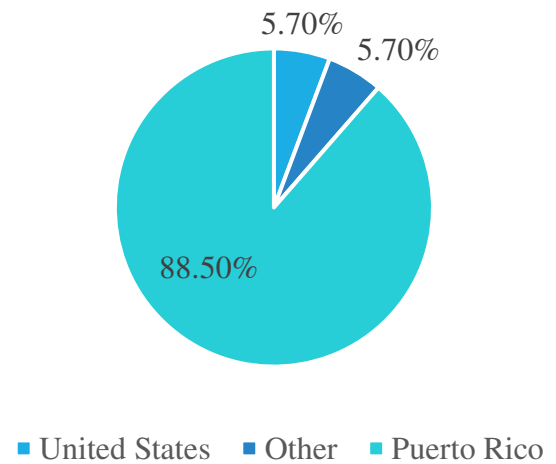
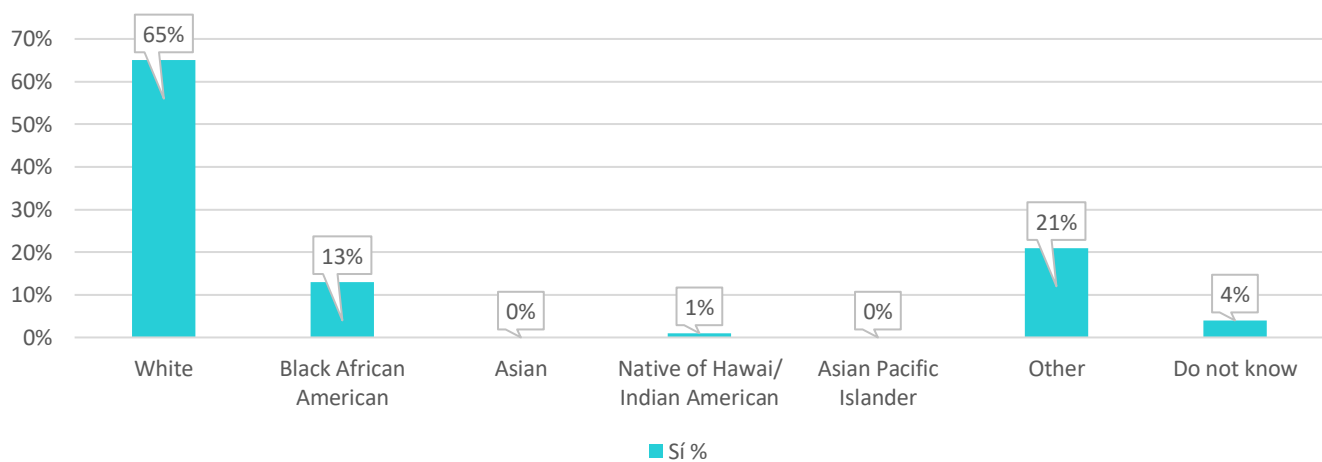
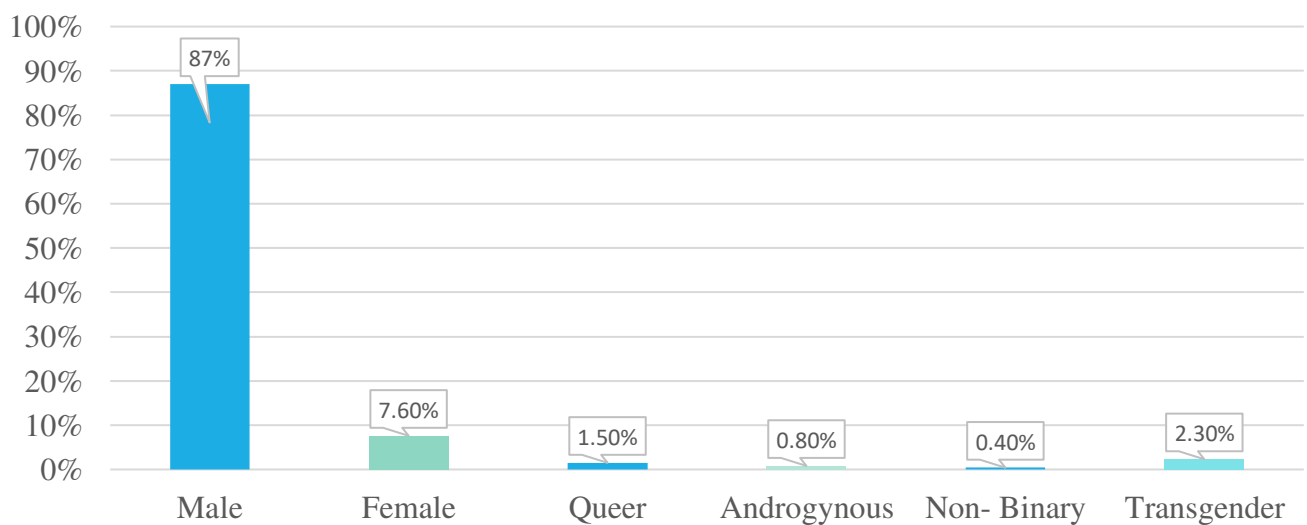
RESULTS

Demographics

Puerto Rico has a culturally and demographically diverse populace, and the aim of this study was to examine the needs by age, race, sex, and gender identity. Socio-demographic data of the study participants are stratified by marital status and family structure.

Participants

We collected a total of 509 surveys. Of those, 264 met eligibility criteria. As Figure 1 shows, their ages ranged from 50 to 78 with an average age of 57. Most were born in Puerto Rico (n=232) as shown in Figure 2. The majority endorsed “white” as their race (n=65). There were 230 males (87%) and 20 females (7.6%). The remaining identified themselves as queer (n=4) androgynous (n=2); non-binary (n=1); and transgender (n=6).

Figure 1: Demographics: Age**Figure 2:** Place of birth**Figure 3:** Race**Figure 4:** Gender

The map of Figure 5 shows, the distribution of respondents across the island. A total of 49 municipalities were represented in the survey.

Figure 5: Sample distribution: Puerto Rico

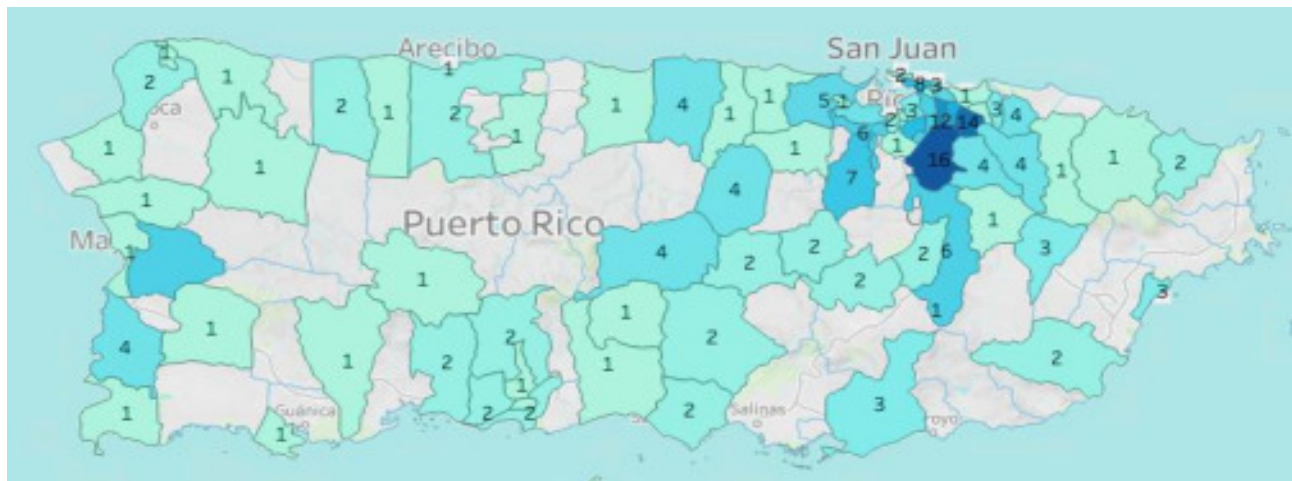
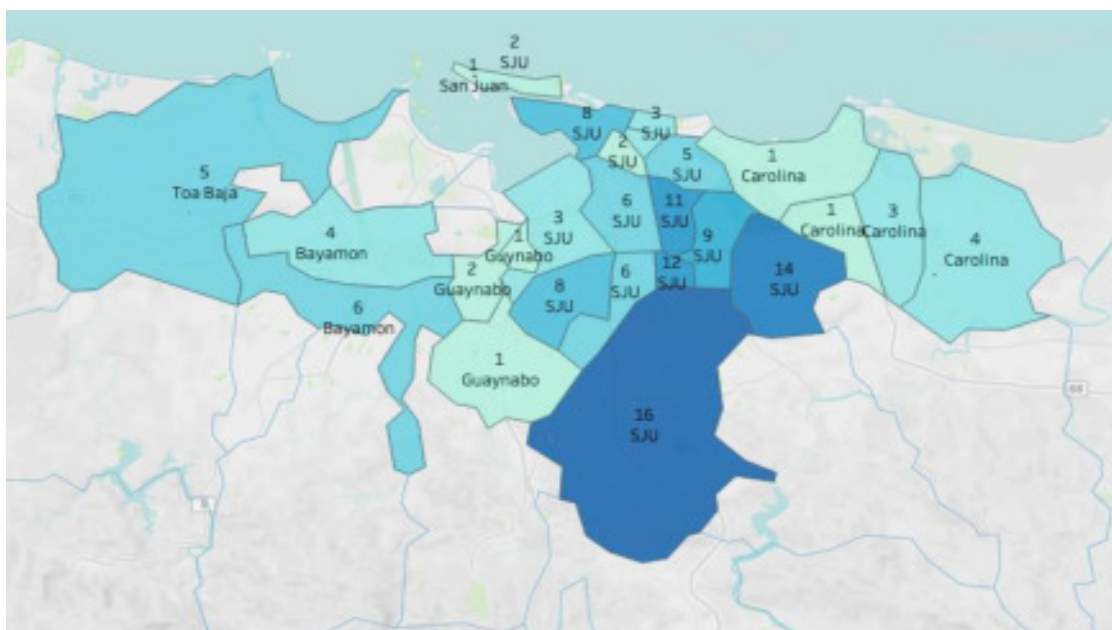


Figure 6: Sample distribution San Juan



Respondents (by zip code) in the San Juan Metro Area

Note. There were no statistically significant differences in the needs for services between those that resided

in the San Juan Metro Area and those that live in other parts of the island.

Social determinants of health

According to CDC, social determinants of health (SDOH) are conditions in the places where people live, learn, work, and play that affect a wide range of health and quality-of life-risks and outcomes. These circumstances are shaped by the distribution of money, power, and resources at global, national, and local levels.

Figure 7: Social determinants of health



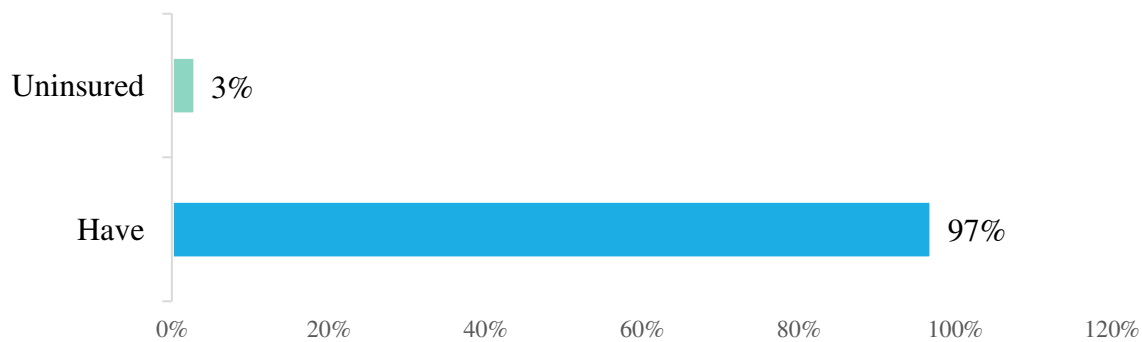
Note. This infographic summarizes how SDOH can be grouped into 5 domains: (1) Education Access and Quality, (2) Health Care Access and Quality, (3) Neighborhood and Built Environment, (4) Social and Community Context and (5) Economic Stability.

The following group of results illustrates the social determinants of health or the characteristics of the life context of the participants that appear to affect health outcomes.

Health Insurance

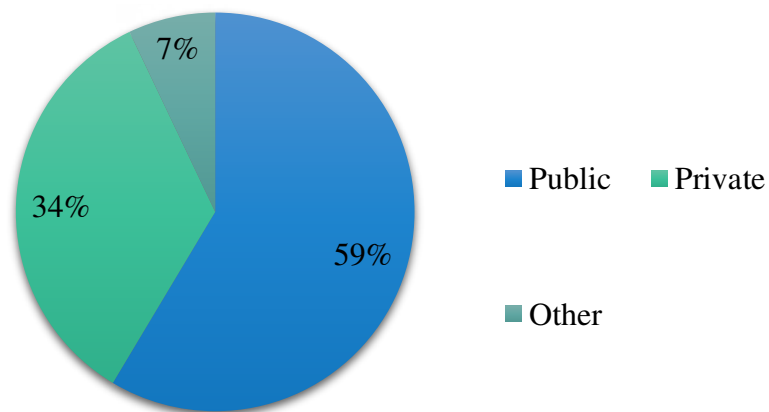
Public health insurance is insurance that is subsidized or paid for entirely by public government funds. Private health insurance is paid for in part or entirely by the individuals being covered. Several different options of private health care insurance are available in Puerto Rico, but public health insurance is mostly provided by the government for low-income individuals or families, the elderly, and other individuals that qualify for special subsidies.

Figure 8: Health insurance



Note. The vast majority of respondents (97%) had health insurance.

Figure 9: Medical insurance distribution



Note. Most of the respondents had public insurance. Those identified as *Other* had a combination of public and private health insurance.

Transportation

Figure 9: Transportation

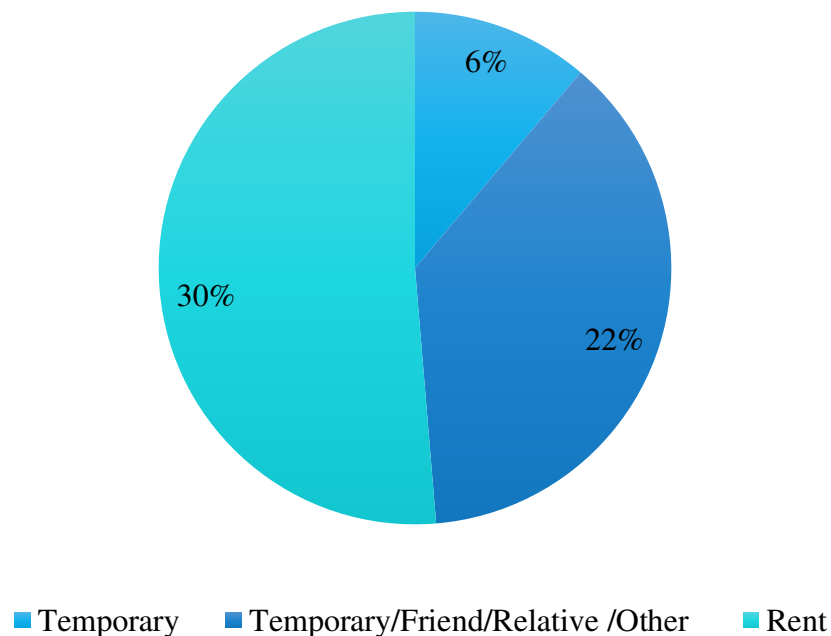
About 1 in 4 respondents lack transportation.

**Housing**

Approximately half of the respondents own their own home, while a third live in a rental property. In a separate question, 21 participants stated that they did not know where they would sleep tonight.

Figure 10: Housing

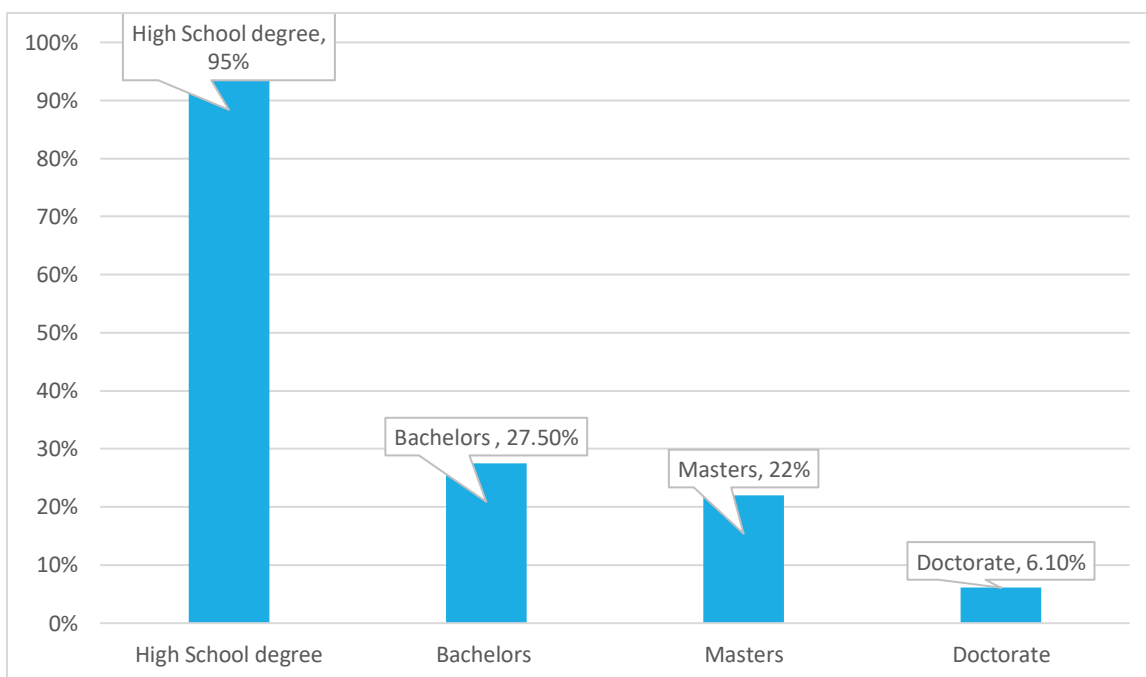
Participant's housing status



Education

As shown on Figure 10, this sample had a high level of educational attainment. Approximately 85 percent have completed a year or more of postsecondary education after high school. There were 58 respondents with a master's degree and 16 with a doctoral degree.

Figure 11: Education



Note: Educational level of respondents

Employment

One in four respondents were unemployed, whereas as 45% were either employed full-time (37.8%) or part-time (7.6%)

Figure 12: Unemployment

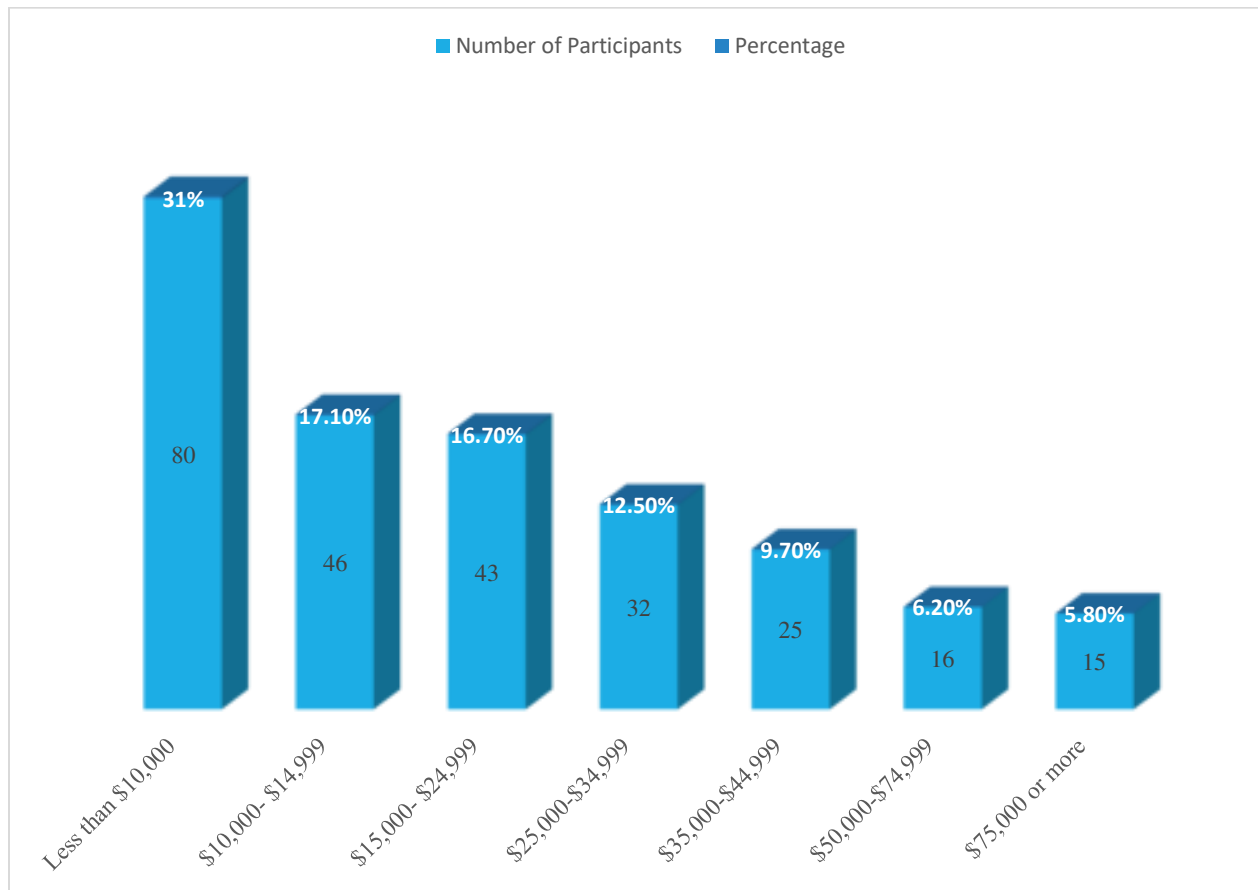
Unemployment ratio: 1 in 4 respondents were unemployed



Annual income

Approximately half of the participants (49%) reported an annual income of less than \$15,000.

Figure 13: Annual Income



Respondents indicated that they still have unmet basic needs that create problems for living. Figure 14 exposes the most pressing needs: (1) eating less than what they thought they should eat because there was not enough money for food (36.20%), (2) the concern that in the next 2 months they will not have a stable home (23.90%), and (3) being left without medical attention because they had no way to get there due to transportation problems (21.80%). In other words, the social determinants of health and the necessities of life that are the greatest problem for adults over 50 years of age or older who are HIV positive are food, housing and transportation.

Figure 14: Service Needs

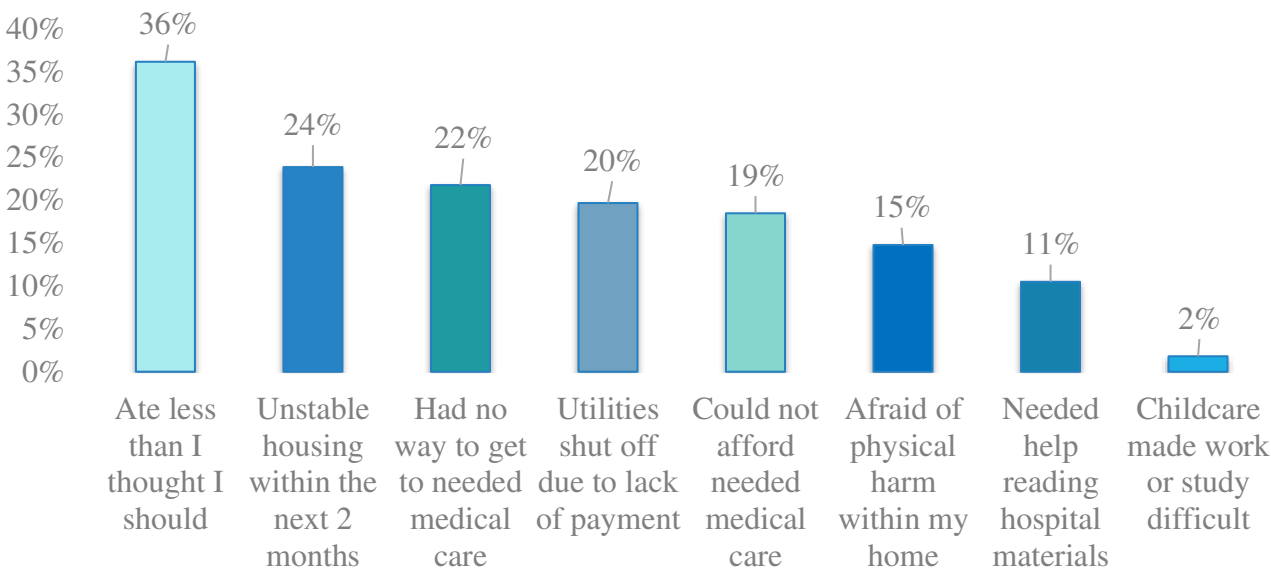


Figure 15

Ratio of participant’s food insecurity



Note. About 21%(n=56) of respondents endorsed “do not have any food for tonight”

Figure 16: Housing status

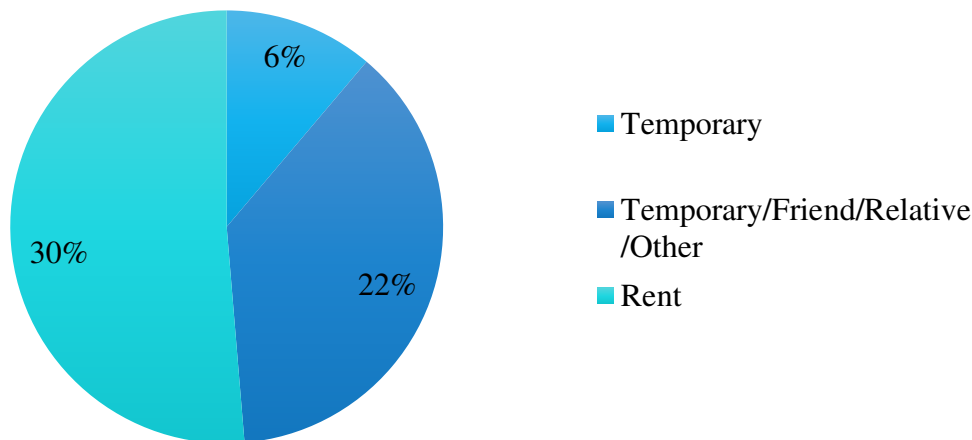


Figure 17: Housing

Note. About 8% (n=21) of respondents endorsed “do not have anywhere to sleep tonight”.

Health needs assessment

The qualitative data (interviews) and quantitative data (264 survey responses) of the needs assessment are outlined in this section. Although the research team strived to collect both types of data for every theme, that was not possible because, in some instances, no significant qualitative themes emerged. This section is divided into five areas: Service Provision, Mental health, COVID-19, Access to Care, Housing, and Information Technology.

Service Provision

Participants voiced their levels of satisfaction and dissatisfaction with health. Some lauded the laboratory services, appointment system, costs, and the qualities of the providers. They praised providers they felt showed respect for patients, particularly the use of a comprehensive approach to service delivery, meaning facilities in which they could obtain different type of services under one roof. Others were dissatisfied with the waiting times and described service delivery as chaotic. The need to involve the patients in service delivery was highlighted by some participants. Some mentioned the importance of integrating complementary and alternative medicine with standard biomedical practice, pointing to the availability of CAM services in the mainland United States as an example of the better services offered there.

Points of Satisfaction

Respondents reported varying degrees of satisfaction in several areas, including cost, appointment systems, laboratory services, services provided by staff, services from providers, and community services. Below are some sample quotes from participants, highlighting some of the strengths of the current program:

Table 1

Qualitative data excerpts from interviews expressing satisfaction

Themes	Sample Quotes
Cost of services and Appointment Process	Right now, my cost is zero dollars. Zero...and the services are excellent in the migrant clinic; excellent...at least with me. Another thing that...has made me feel comfortable there is that appointments are scheduled, you go to a place where there are few or no people, you do not cross paths...everyone is sitting there, waiting
Satisfaction with Staff	<p>It is good, the staff is very good, very efficient, and very good. I am not complaining. The only thing that, as always, as they work with a lot of federal funds, they are drowned in papers.</p> <p>Well, I do not complain about the services there, because they are very complete... now they have a nutritionist who sees you, too, evaluates you. They have a psychologist who made an appointment for me precisely to these days. They have the pharmacy right there to get my medicines, they have the laboratory that I use right there. My only complaint there is the parking.</p> <p>I feel very good, because I have been there for years. I know the staff, the staff knows me. They are very kind.</p>
Satisfaction with Doctors	Right now at the agency I attend I feel good, very comfortable there. I feel like the doctor listens to me, the doctor is open to dealing with other situations, not necessarily just my condition as a gay man with HIV, right? Because as a gay man with HIV I need to talk about certain things that are happening to me, such as an erectile problem. I still have an active sex life and it is frustrating, So then, I talk about those things with him. So I have had opportunities to have, to acquire certain medications, such as testosterone. Now that it is the first time that they are going to prescribe injectable testosterone to me, because my testosterone is very low. And that because it seems to me that with that doctor, I have better communication; he knows me, I talk to him about

Themes	Sample Quotes
	<p>everything, which is good. For me it is very important and necessary, because you need to feel comfortable with a doctor.</p> <p>My Doctor, he is a great human being. His quality as a human being [is that] he negotiates with you, explains the pros, explains the cons.</p> <p>With the doctor, he is super friendly, super attentive, a person who listens, who not only listens, who is also open to comments and suggestions.</p> <p>Maybe at first I got a little nervous, but then later, I felt good, I felt confident. And he has helped me a lot, because apart from being my doctor, he is also a friend, I consider him a friend.</p> <p>I had been recommended by the director of the Center. I have to say that he has the peace, the tranquility, the patience to be able to attend the patient. I feel comfortable with him.</p>
Satisfaction with Services	<p>And so, I start at the migrant clinic, and the services have been, my goodness, super, super, super, in terms of the laboratory, in terms of the medications, that I currently take, in terms of follow-up, although the doctor recently resigned...There is no proper doctor. Even so, even so, everything flowed well.</p>

Areas of Dissatisfaction

Despite overall satisfaction with the staff and providers, respondents reported dissatisfaction in a number of specific areas, including waiting times, patient involvement in research agendas, patient respect, and the broader health system:

Table 2

Qualitative data excerpts from interviews expressing dissatisfaction

Themes	Sample Quotes
Dissatisfaction with waiting time	I have always seen constantly that everything is full, full, full. And...if I need to go because it is something that does not merit an emergency room but merits that a doctor see me today, well, then there is a problem...And I believe that this should be reviewed because it can represent a high level of anxiety for a person who has a situation that must be addressed urgently
Calls for patient involvement	... HIV does not have colors...we must, you know, also integrate patients into projects... because nobody knows what you have lived, more than the one who lives it.
Importance of respect	Don't let them [patients] come to waste their time. Because here... unfortunately the patient is disrespected. When you schedule him at eight in the morning...and the doctor shows up at eleven o'clock, that is disrespectful to the patient.
Unsatisfied with health system	Chaotic, chaotic, the health system, both private and public, is not prepared to face one more epidemic.
Mentions availability of alternative services as a standard to compare services in PR with those in the USA	All those therapies are gone. I used to go, in New York, for example, there was acupuncture for people with HIV. In California, in San Francisco, you know, there were some places that you went and they gave you acupuncture at a very low cost, because acupuncture is expensive. They gave you all kinds of services. There was a place in New York that you would go and eat organic food...And those services no longer exist. Here [i.e., Puerto Rico] there was also that, here, this, they offered you massages, dental, all those things that I don't know why they no longer exist, they no longer exist.

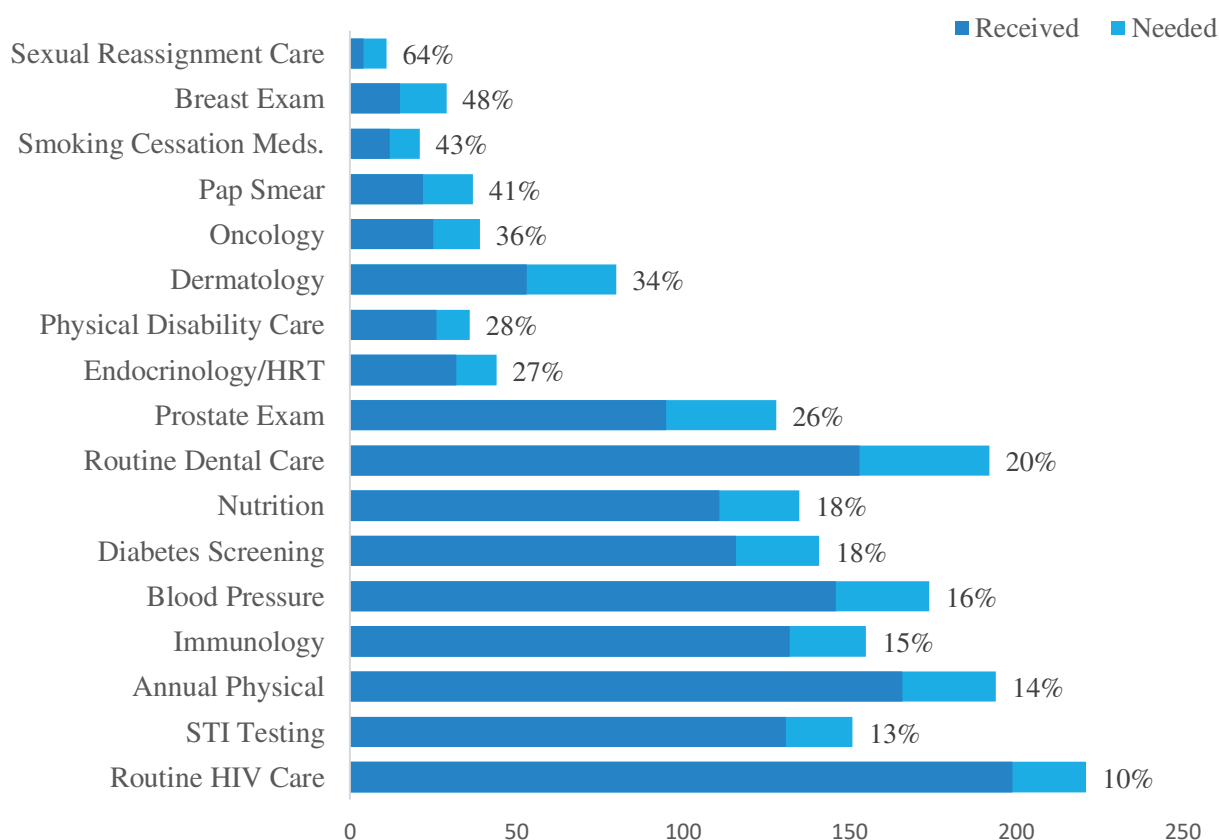
Discussion: Service provision

Across respondents, a number of crosscutting themes emerged that speak to an overall dissatisfaction with health services and a significant amount of unmet need.

Accessibility of specialized health services

Among those surveyed, up to 64% of people reported they did not receive a specialized service they said they needed. Specialized services in sex reassignment (63.6%), breast examination (48.3%), medications to stop smoking (42.9%) and pap smears (40.5%) were particularly difficult to obtain: between 40% and 63% of the people reported that they needed these services and could not receive them in the past year.

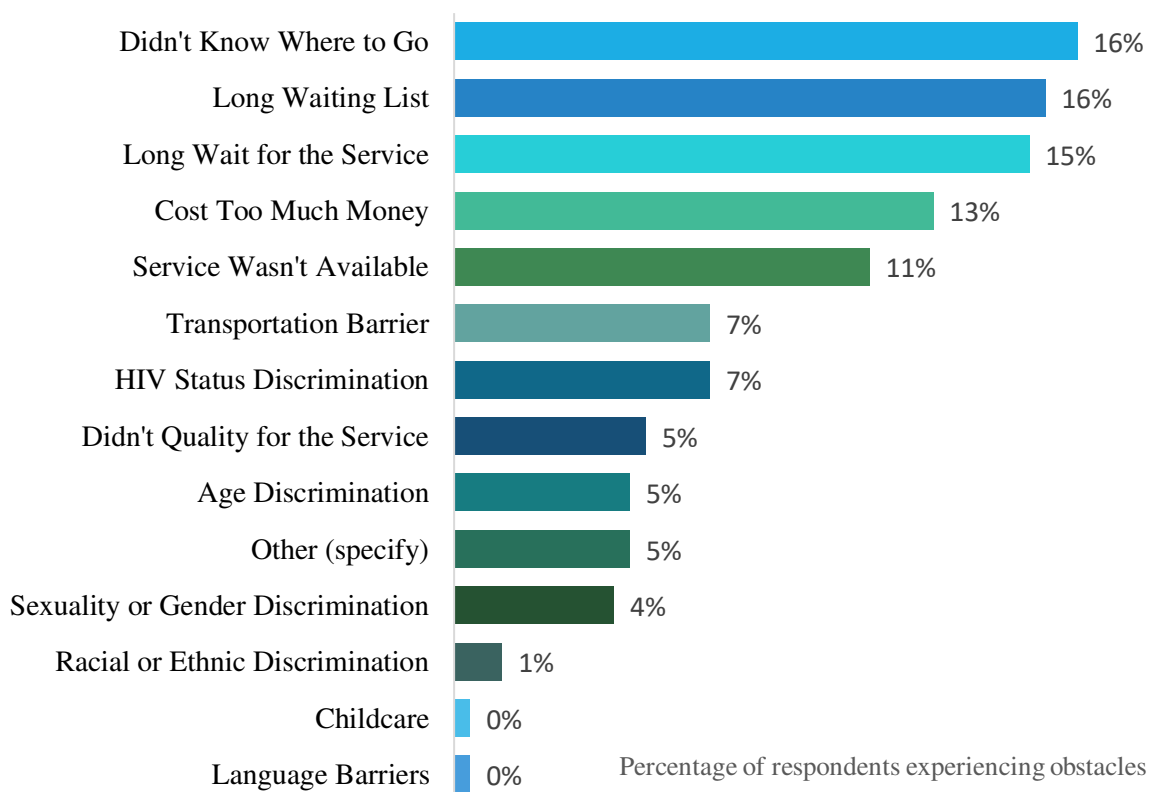
Figure 18: Barriers to services



Barriers to Health Services

Respondents stated that the most significant hurdle they encountered was a lack of knowledge about where to receive the services. Yet even those who were aware of the need for services and knew where to obtain them were confronted with lengthy waiting lists, discovered that the service was not available, or were unable to afford the services. Discrimination (based on age, sexual orientation, or race) was reported by less than 5% of those who answered the survey questions.

Figure 19: Most common barriers to access services



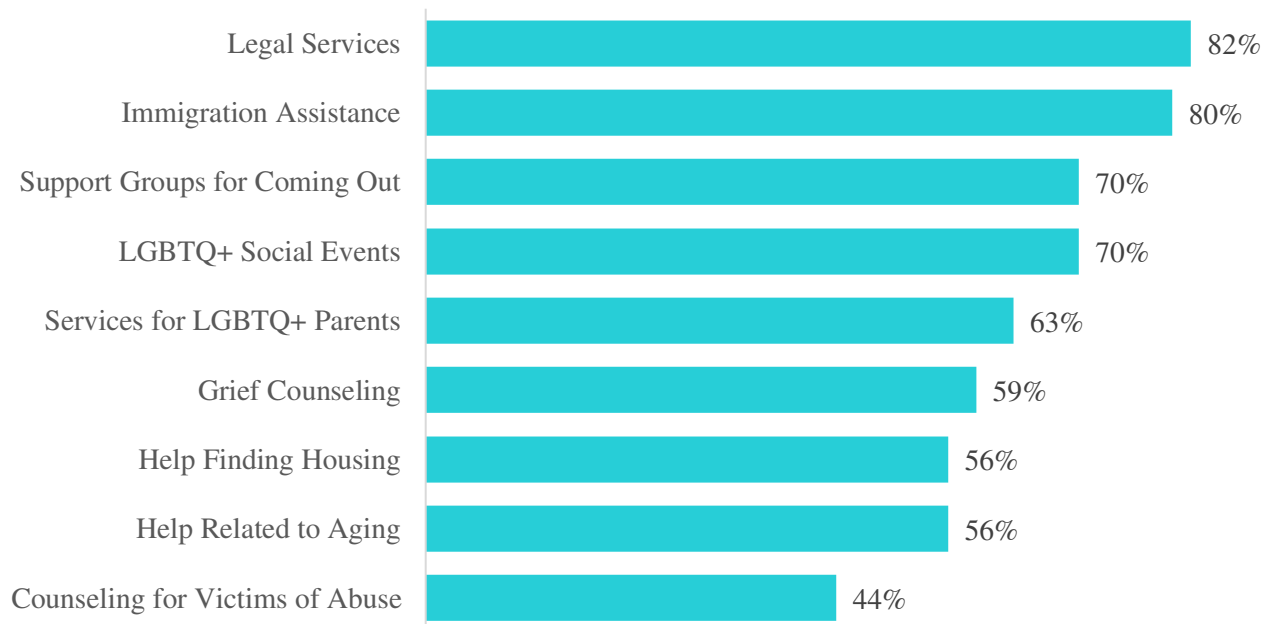
Difficulties obtaining social and community services

Obtaining social and community services was also a difficult task for these survey participants. Two out of every four participants who reported needing counseling as a result of being a victim of violence were unable to obtain it. In the survey, more than half of individuals who needed assistance with aging, housing, or grief counseling did not receive it, and around 7

out of 10 of those who needed LGBT+-related services did not receive them. Legal services were reportedly the most difficult to obtain.

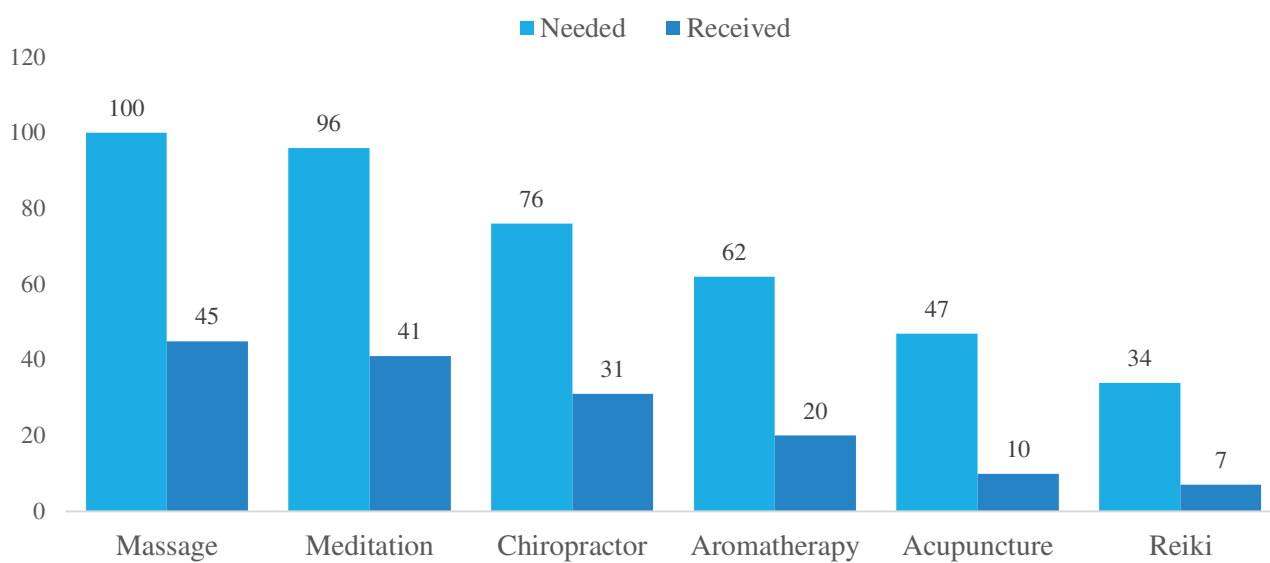
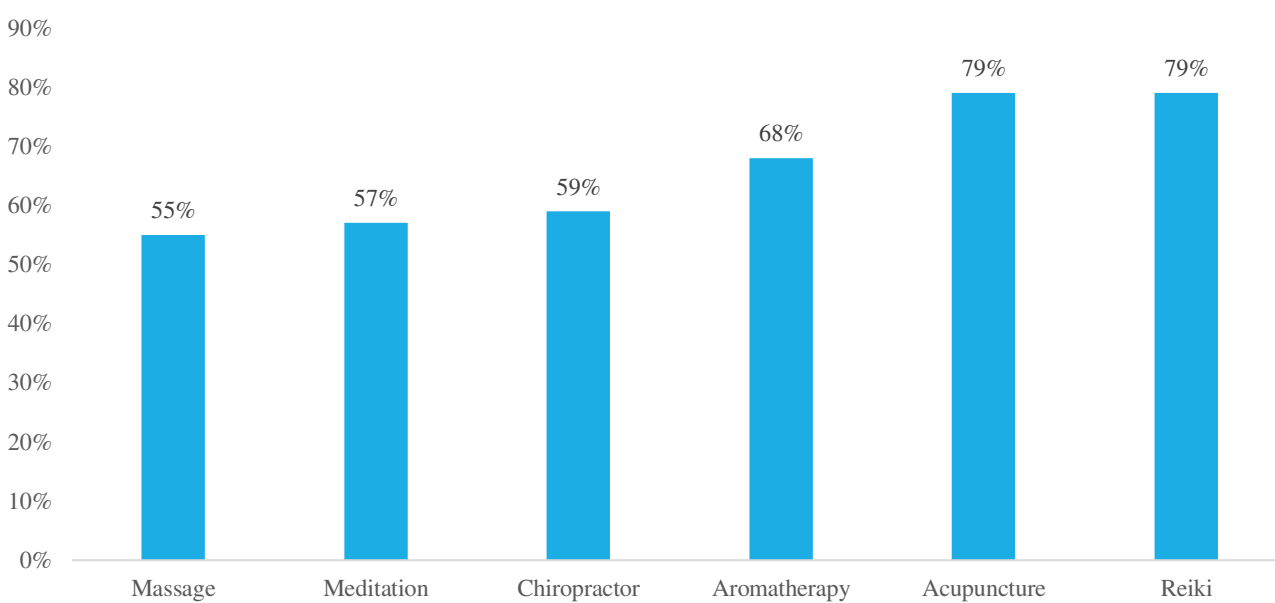
Figure 20: Social and Community services

A. Percentage of respondents who needed but not received social and community services



Complementary and alternative medicine

As showed in Figure 21, respondents indicated that among all complementary and alternative services, such as massage, meditation, chiropractic care, aromatherapy, acupuncture, and Reiki are the least accessible. More than 50% reported they were unable to receive the complementary services, with 78.7% reporting acupuncture and 79.4% reporting Reiki as unmet needs.

Figure 21: Complementary and alternative medicine services**A. Number of respondents who needed and received services****B. Percentage of unmet needs**

QUALITATIVE DATA ANALYSIS

Below we present results from the qualitative portion of this study, which consisted of open-ended interviews conducted with 13 area residents. A summary of illustrative quotes representing the identified themes from the open-ended interviews are presented in the table below.

Qualitative data: Mental health

LGBT+ adults are known to have elevated risk for mental health issues due to societal stigma and the effects of homophobia.¹¹ These risks have been compounded during the current COVID-19 pandemic, intensifying the struggles many LGBT+ adults are facing. The quotes in the table below illustrate the experiences of respondents with mental health conditions, specifically depression and anxiety, during the COVID-19 pandemic. Several respondents mentioned sources of their distress in addition to the pandemic, which included taking care of a parent, experiences of the earthquake, difficulties accessing care, lack of sexual activity, financial strain, accessing food, loss of social support, learning new technologies, and disruptions in the public transportation system. One participant was concerned that his distress would affect his CD4 count.

Table 3

Qualitative data excerpts from interviews about mental health

Themes	Sample Quotes
Depression	[During the pandemic I feel] depressed. Unfortunately, [life is] very hard, because I am at home. I do not go out, I do not share. [I go] from my house to the supermarket, to the doctor and back home.

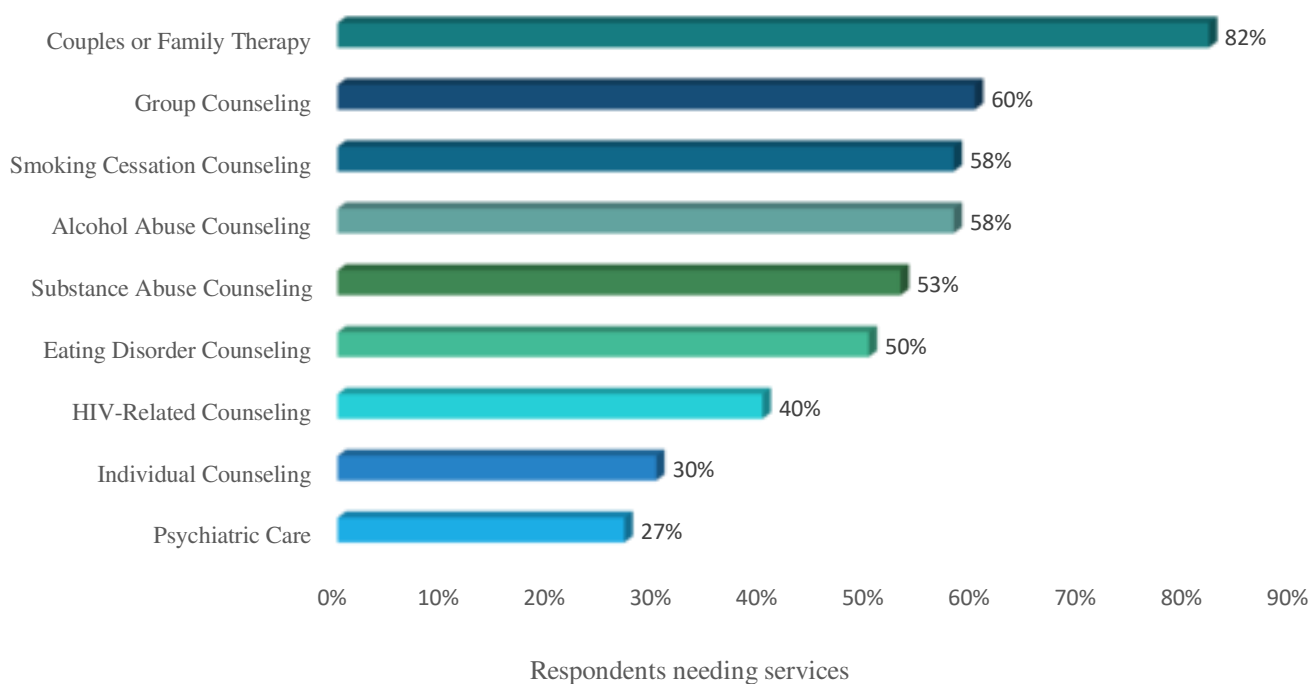
¹¹ Tinney, J., Dow, B., Maude, P., Purchase, R., Whyte, C., & Barrett, C. (2015). Mental health issues and discrimination among older LGBTI people. *International Psychogeriatrics*, 27(9), 1411-1416. Accessed August 7, 2021

Themes	Sample Quotes
	[CoVID-19] has affected everything...We have had to change our lifestyle completely. It has affected as much mentally, many people became depressed. It has affected us in every way.
Anxiety	I felt afraid, less confident in the street.
Source of Stress:Finances	Because nobody gives me anything. I realized in 91... that the bills keep coming, in the one from the water company and the electric company. It does not matter if you are dying, they keep sending you the bills. That year..., I entered a depression, [so bad] that I wanted to die. Thank God...it turned out well.
Source of Stress: Exposure to Violence	I am not afraid of jail, because I have lived most of my life in it... [T [his, but this last time I saw that a Cuban guy was picking on a gay trans girl, and he had her bare-knuckled in the floor, and I'm telling him, "Look, you already hit her, you already have this, leave her be." And he pushed me and he pulled me. And, well... I always get in trouble, always. I don't like mistreatment.
Poor Service Quality	... I know that we, patients with HIV, are very affected by our emotions. The psychologists who are there have not done anything for me; that is, I am no longer making appointments for the psychologist, because, really, I feel that they are not helping me.
Coping with Mental Health Conditions	<p>I am a survivor of many things, including HIV, and a heart operation that I had when I was very young...There are many things and many obstacles that life has faced me with .</p> <p>I am a person, I am a strong person, but I am a Christian person...everything that I went through and everything that I have gone through...what I have done is pray, asking God for strength. And I tried not to think about it during quarantine when I couldn't see my friends. What I did was I started cleaning the house, I started organizing it. The time comes when that also tires, but it was the best way to avoid depression and to avoid the sadness that I could not see ... my</p>

Themes	Sample Quotes
	<p>friends, that I could not see anyone. So, I clung to that and to prayer, and ...I was able to cope with the pandemic in everything.</p> <p>The poor [person's] psychologist is Facebook, They get in there, they vent, and they cry, people criticize, they speak.</p>

Despite these mental health challenges, mental health services were difficult for most respondents to access. Individual counseling was not available to approximately one out of every three respondents who required it. Most significantly, about 4 in 10 respondents were unable to obtain HIV-related Counseling Services. Older LGBT+ adults who are not able to access needed mental health services seek other ways to alleviate their emotional discomfort, with social networks being the most mentioned alternative among the interviewees:

Figure 22: Mental services needs



Health services: Met needs

We studied what factors were associated with having one's needs met. Four new variables were created to assess four different categories of need: medical services, complementary services (such as acupuncture or massage), mental health services, and social services (such as housing or legal assistance). Variables were created by calculating the percent of services each participant received within that category. Needs were then tested for association with age, living in the San Juan Metro area, and education level. For simplicity, education was re-stratified into the following categories: high school diploma or less, some college or bachelor's degree, and master's degree or PhD.

To test the association between age and unmet needs, Pearson correlation coefficients were calculated and not found to be significant. Age did not appear to be associated with getting one's needs met. Similarly, to test the association between living in the San Juan metro area (a binary variable), Point-Biserial correlation coefficients were calculated, and again, the associations were not significant. Access to services did not appear to be associated with which part of Puerto Rico the participant lived in.

To assess the education level with needs, Kruskal-Wallis tests were performed. The Kruskal-Wallis test identifies whether the medians across independent groups of unequal size are significantly different from one another. The Dwass, Steel, Critchlow-Fligner post-hoc method was used to identify which specific groups had significantly different medians. No differences across groups were identified when it came to mental health or social service needs. However, medical needs and complementary service needs did differ by education. Specifically, those with some college or a bachelor's degree were significantly less likely to have their needs met than those with a high school education or below. Upon further analysis, this was not due to college-educated participants identifying more needs than their high school educated counterparts, as both groups identified a similar number of needs in both of these categories.

Qualitative data: COVID-19

To prevent the spread of COVID-19, social distancing measures were implemented, increasing isolation and making many older adults feel lonely, anxious, worried, and fearful. Many reported

increasing their use of technology to access social networks in order to socialize and connect with acquaintances.

Participants also described the COVID precautions they took and recalled lessons learned from the AIDS epidemic. Some of the participants provided examples of how they coped by practicing self-care and discovering opportunities to do creative things online. Not all coping strategies were adaptive: one participant reported drinking more alcohol during quarantine. Respondents were aware of COVID-19 misinformation. All respondents were vaccinated and reported being aware of the value and importance of the vaccine. The table below shows sample quotes further illustrating those findings.

Table 4

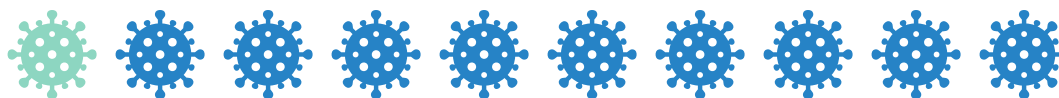
Qualitative data excerpts from interviews related to COVID-19

Theme	Sample Quote
Alcohol use	I increased the consumption of liquor a little...I was consuming a lot of alcohol at home....There it is, precisely, because I can't drink a bottle of wine, two bottles of wine in a week, normally. A whip and a drink tomorrow, a bottle on a Sunday, I can have some whiskey. But there was a time when I was drinking three bottles of whiskey in a week
COVID Coping examples	<p>Exercising, watching movies, thinking positive, and speaking on the phone with friends, praying. Also, asking God that this end soon, that he takes care of us, that the pandemic ends. And then...[trying] to distract myself,... change my environment, going out, so as not to be in the house all the time, you know... And at the same time, because there I can socialize, right, with the small groups of friends, we are already like a family, we have known each other for many years.</p> <p>I am a person, I am a strong person, but I am a Christian person...everything that I went through and everything that I have gone through...what I have done is pray, asking God for strength. And I tried not to think about it during quarantine</p>

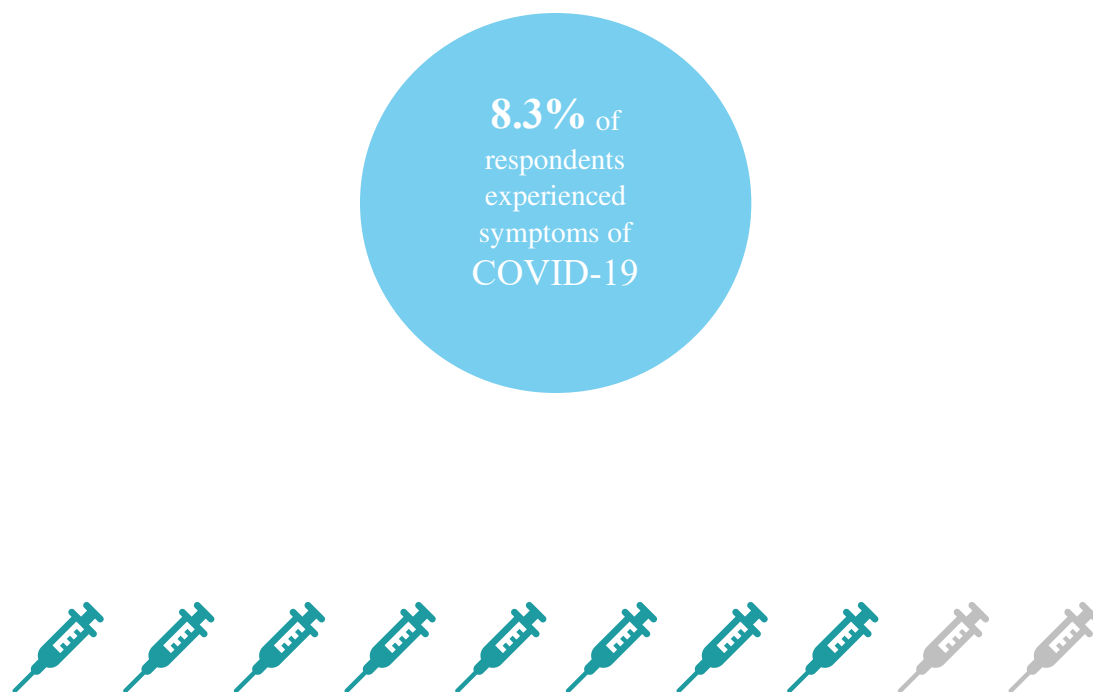
Theme	Sample Quote
	when I couldn't see my friends. What I did was I started cleaning the house, I started organizing it. The time comes when that also tires, but it was the best way to avoid depression and to avoid the sadness that I could not see ... my friends, that I could not see anyone. So, I clung to that and to prayer, and ...I was able to cope with the pandemic in everything.
COVID-19 Earthquake Coping mechanism: Survival mode	Building. Even once we all went out to the streets and we were there pending because the earthquakes were very active. ...I think that through all these experiences, that I already took them as a matter, that is, I put myself in what is called survival mode.
Disruption of medical care	Because of the pandemic, they could not do the tests. And if I noticed something strange, go to the emergency, that's what they told me.
Disruption of everyday necessities	[T]he transportation... that stopped. I had to shop, sometimes, you know, load the packages, because you have to put yourself in the place of everyone, you are the one... [I]t is very real, you understand. There was no public bus
Financial strain	Well, financially, it has really hit us hard, because we can't work, we can't go to workshops, we can't travel to be able to follow the workshops And in food, well, we have to wait with fear for a supermarket, that someone infected with COVID and you do not know, you have to protect yourself.
Lessons learned from the AIDS epidemic	Do you know what else I could think of ...? That we had not gone through a pandemic like this before, I think. We have lived through the very strong times of AIDS. That also gave us many lessons, that in a certain way we also had to adapt, right...to make changes in our life routine. We went through that experience where we lost friends, family. It was also a moment of loss, as now with this COVID thing. So it was also a quite difficult stage. We had to make adjustments and have a lot of patience, because at a certain point we did not have medicines, either, to treat it, as now in the pandemic...At the beginning there were no vaccines and there was a lot of uncertainty and we saw many people die, which perhaps, that also has not helped

Theme	Sample Quote
Loss of employment or income	<p data-bbox="418 268 1450 632">They call me [and said], “You lost your job. Fired, and we compensate you.” I lost my status, lost the doctor, for now...I already checked the inventory of the medicines. I have medicines, I can survive a month and a half more because I have medicines, I had medicines left still...They call me...and tell me, “You have a refill available,” and I say, “How? But I don't have a medical plan.” “No, no, here it appears that it is covered...there is a refill of three more months.” “Send it to me, send it to me.”</p> <p data-bbox="418 705 1450 909">Due to the pandemic, the income went to zero completely, everything was delayed. Even today, I still have my accounts all in arrears, but because people know that...I am paying as much as I can, [they] have been able to understand. But it is not easy.</p>
Loss of social/family support	<p data-bbox="418 930 1450 1125">[The thing I most want to do when the pandemic is over is] hug my family, kiss my loved ones, even good friends that I know I have. Because we are beings of love, and we Puerto Ricans are very expressive, and that is a little thing that I, at least I miss.</p> <p data-bbox="418 1199 1450 1394">The biggest obstacle there has been is not sharing with people, not going to your mother, you have to go far. You don't work, because they don't let you in. You have to find the way... to speak from afar or by phone...there is no communication between human beings.</p> <p data-bbox="418 1467 1450 1623">[M]y grandmother, she is ninety-two years old and lives in Lares, so, it is not that you do not want to visit her, it is that you cannot. [She is] ninety-two years and she there did not have the ability to get vaccinated.</p>
Physical and Social isolation	<p data-bbox="418 1644 1450 1728">The biggest challenge is direct physical contact with family or friends...[T]his is the biggest challenge, limiting physical contact.</p>

Theme	Sample Quote
	Well, it limits contact with family or with other people, [and] although there is already more openness, it limits you to limited spaces for social sharing in person.
Source of distress: fear	Well, I have been afraid, because...we are human beings and we are afraid that something will infect us.
Motivation to get vaccinated: Caring for older parent	I live with my mother, who is seventy-four years old. [I worry about bringing] COVID from going out or doing something on the street...Because your responsibility also has to be with yourself, you understand. We are more at high risk, due to defenses, respiratory problems. I said, "If there is a vaccine, we are going to get it."
Motivation: realized its importance	I was there. I was one of the first, there in the medical center, in December. I want to be vaccinated...It was because I read a lot and also [listened to] many lectures on the vaccine, and I understood that it was a safe process...[N]ot like many people commented out there, [that] they did this very quickly. No, there were processes, the studies that were done, in applications for cancer. And, well, they applied them for the vaccine now. [I got vaccinated] to end the COVID thing...I got vaccinated because I knew it was very important to get vaccinated. And for me the vaccination was, that is, I got the vaccine already and there I started my campaign with my mother and my brother. The most difficult was my mother, but we succeeded and none of them, thanks to the universe, none of them [got COVID]
Motivation: Peer pressure	Peer pressure really [motivated me to get vaccinated]. I didn't want to, but in my house everyone got vaccinated and they literally forced me to get vaccinated.

Figure 23: Covid-19 positive results

Note. About 1 in 10 respondents reported experiencing Covid-19 symptoms or had received a positive result for a COVID-19 test in the 12 months prior to completing needs assessment

Figure 24: Covid 19 vaccination

Note. About 8 in 10 have been vaccinated in the 12 months prior to completing needs assessment.

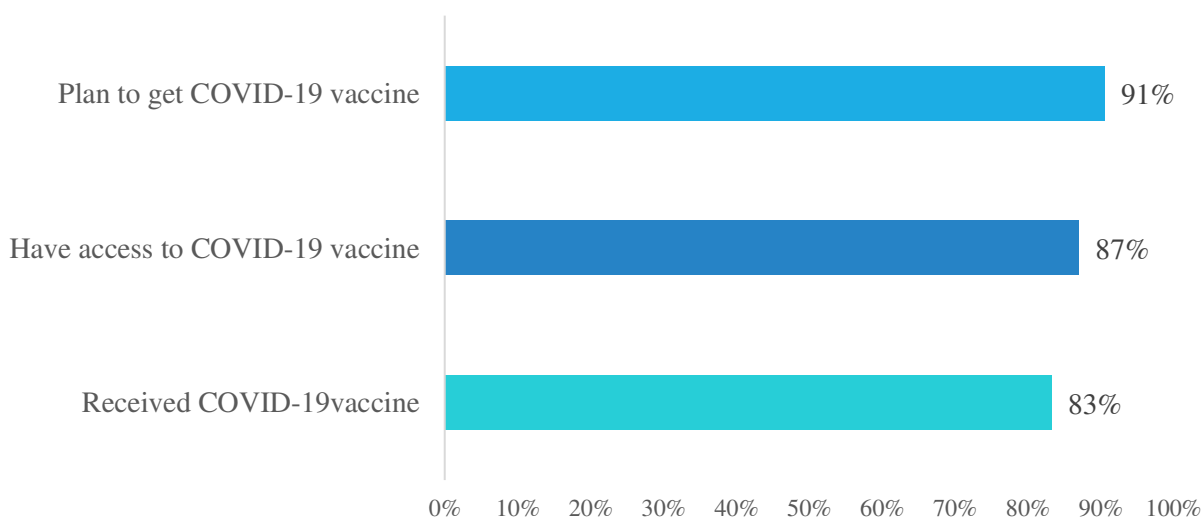
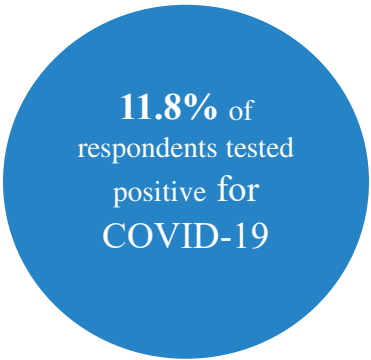
Figure 25: Covid-19 vaccine

Figure 26: Symptoms and positive results for Covid 19



Qualitative data: Housing

Referents to housing point out to the need to define what is meant by “stable housing;” not only what it is (a place to go at night), but also what it implies, i.e., that the person has a source of income. The other mentions of housing were related to the loss of a home due to the natural disasters that visited the Island in recent years such as the earthquakes and the hurricanes.

Table 5

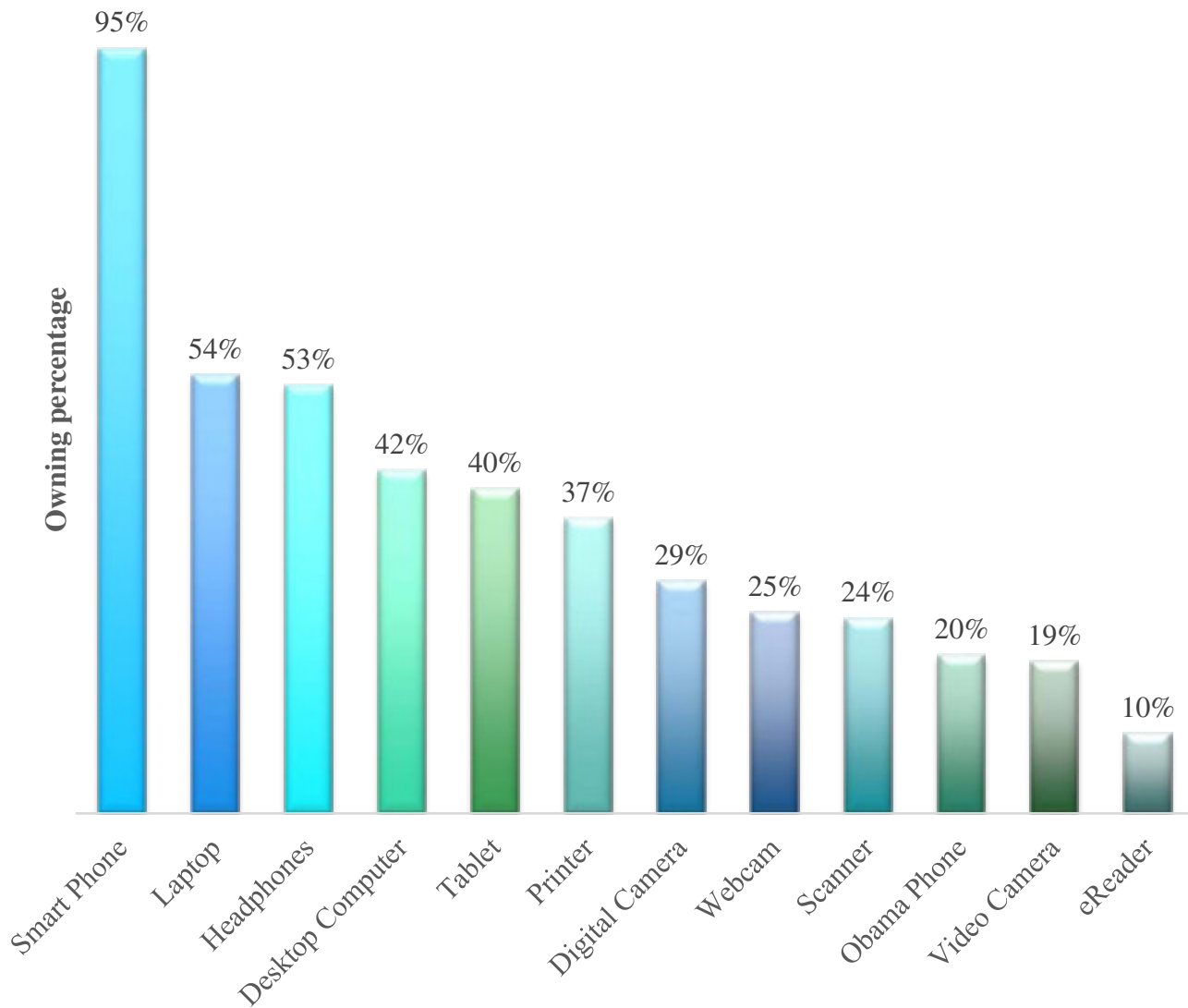
Qualitative data excerpts from interviews related to housing

Themes	Sample Quotes
Defining housing	Well, stable housing depends on how we define it, if we talk about owned or rented housing, because “stable” is that I have somewhere to go every day. It does not necessarily have to be mine. But, in any case, accessing stable housing implies economic income, it implies many other elements that, if they are not present, will be very difficult
Losing home as a result of hurricane	Look, it's very interesting that you ask me that question, because we went through Maria. And María, it was very difficult, María, you know, we were without light for a long time... And I immersed myself in helping people in the community. I went with a brigade to collect rubble, to remove the trees from above the houses. I even went to... bring meals to the victims...After Maria, well, we also lived the question of

Themes	Sample Quotes
	<p>earthquakes. Those were a couple of weeks dealing with that, with the uncertainty that there was...even at night [I] could not sleep, because I thought that an earthquake was going to come.</p> <p>But the hurricane completely destroyed it, the only thing that is standing are the walls. And it is very difficult to seek help, I have actually sought help even in the municipality and they have denied me.</p>
Losing home as result earthquake	<p>For example, I had my own stable home for many years. [Then] the earthquake came...and my apartment building has been closed for a year and a half. Right now, I am considering a voluntary surrender to the bank to get out of that property, because we have been in the insurance reevaluation process for a year and a half, and hopefully, if we have it, it will take three to four more years for that building can be fixed and enabled; if not, rather in other earthquakes along the way and finish it off</p> <p>So, I have a stable home at the moment because I live with my partner...because we have a solid relationship, and we live there. But the reality is that my home that is under my name, which I paid for many years, really it is lost, and it has nothing to do with my not being responsible, because I bought a property many years ago. It has to do with the fact that an event of nature arrived, that it was not in my control, and that there are some legal processes that are tedious, that are long, that are complicated, and that, really, they do not guarantee that I can have that housing again.</p>

Qualitative data: Technology

Most of the respondents (95%) own at the very least a smartphone. Slightly more than half own a laptop. Less than half of the respondents own electronic equipment such as a desktop computer, tablet, digital camera, scanner, etc.

Figure 27: Technological devices owned

Comfort levels

Respondents, overall, reported feeling somewhat comfortable using an electronic device.

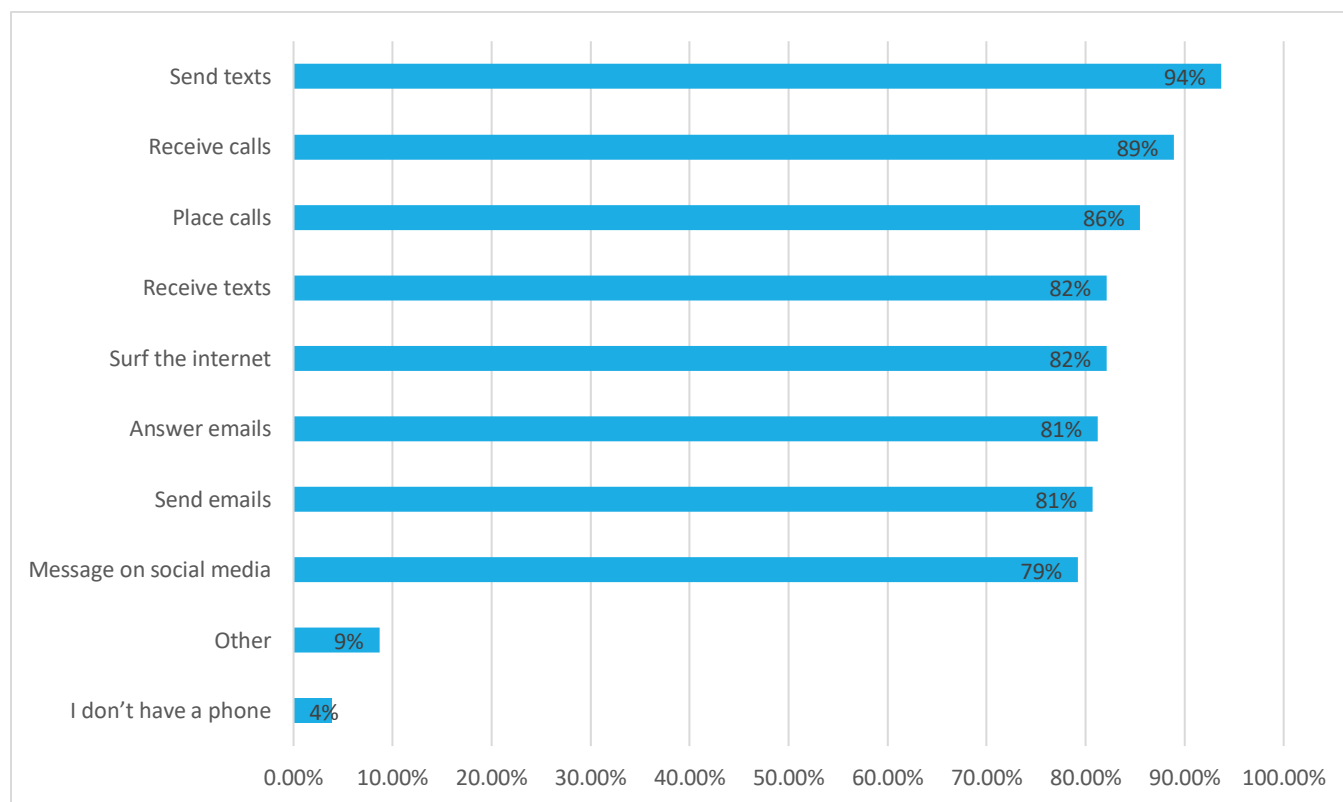
Table 6:

Level of comfort with activities related to technology devices usage

Activity	Number of respondents	Composite score	Composite score level
Using a computer (laptop or desktop)	179	2.33	Somewhat comfortable
Using a smart phone or tablet	196	2.43	Somewhat comfortable
Accessing the internet	193	2.41	Somewhat comfortable
Using email	190	2.43	Somewhat comfortable
Looking for information online	188	2.45	Somewhat comfortable
Using social media	186	2.49	Somewhat comfortable

Telephone usage

The results show no unusual patterns of phone usage. As shown in Figure 29, most respondents use their telephone to send and receive messages, surf the internet, and use email services.

Figure 28: Phone usage according to activity

Participants highlighted their experiences using telehealth, including the use of health applications to manage services. Others mentioned how they use technology to keep in touch with families and friends, keep abreast of the news, engage in learning, find sexual partners, and pay utilities bills.

Table 7

Themes	Sample Quotes
Telehealth	
Entertainment	Facebook, Instagram, Twitter, and lately I'm addicted to Tik Tok. [Interviewer: Perfect. And what benefits do you find from these platforms?]: Facebook keeps me, Facebook keeps me informed of the happiness of others, of the happiness of my cousins...and my uncles, because, well I see it there. I do not share it with them, but I see the photos, and I see. Actually, the family album is

Themes	Sample Quotes
	<p>Facebook, because I don't have everyone on Facebook, I'm very restrained...people I don't know [I] don't want them on my Facebook...</p> <p>Instagram, on the contrary, well, I publish one or another photo of me from some day at the beach or from some <i>hangueo</i> (hanging out), and the whole topic. Everyone who sends me requests I accept, and I see photos: I see boys, I see girls, I see bodies, I see everything, and everything there is to see on Instagram. Twitter, on Twitter, well, basically, I use the Twitter profile to follow people, porn artists, they're on Twitter, now...you see a lot of pornography; pornography that lasts two minutes, but it is pornography. Many people publish photos, and you retweeted it and it is the photo that someone missed, well, fifteen thousand people have already seen it and the photo was spread everywhere. So, I use it for that, but I do not socialize. I don't socialize on Instagram, I don't socialize on Twitter, I don't do dates, I don't do virtual sex, I don't like FaceTime. I don't want WhatsApp to call me by video call, I don't like it...And I don't do sex on camera or on the phone, or those things, no.</p> <p>There's Tiktok. Well look, I do this Tiktok to watch those videos and have fun, because in Tiktok there is everything, I see drag queens, I see artists, I see people--a number of people have come out of Spain. Even when they do the live shows, I participate in the live shows. And when they say they are going to do a show, well, I put if I can the time that they do the show, as there are six hours difference between Spain and Puerto Rico. Well, I go into the show...And there I have made a couple of friends, but people from Alicante, Malaga, the Canary Islands, and Barcelona. And for the time that I have been, well, because we know virtually, Euri, Richie, Alex, Pandora, etcetera, etcetera, etcetera. There I socialize, but no, no... the people of Puerto Rico that I have are very few, almost none, everything is mostly Spain.</p>
Lack of knowledge	Well, the problem is that I did not know... in technology, I am not very good, either, because I did not take a course or anything in technology to be able to

Themes	Sample Quotes
	<p>engage with that. And sometimes I was doing it and it was erased, so I had to start over</p> <p>Well, look, I would like...video. Michel explained to me that there are many workshops, and I don't know how to do any of that... [B]ut I have not taken any workshop, or anything like that. That is, I understand that within technology there is a world, that is, there are no distances, there are no limitations, but my limitation is I don't have the knowledge to enter that system, you know?</p>
News	<p>[Interviewer: OK. And what do you use it for? For example, if you were to say that you use the phone for something specific, the tablet for something specific]. Well, look, the phone is to communicate: calls, text, if I have to answer emails, the social networks, obviously. So, the tablet... I use it when I'm having breakfast in the morning and I put it like that on the table...and I check the news, or I listen to music on the tablet. Or if I have to go somewhere, well I'll take it, I have an iPad mini, which also has a connection. I have a travel agent pay site that I use to sell cruises. I have the tablet. If someone asks me about a cruise, then the tablet comes in there.</p>
Pay utility bills	<p>[Interviewer: You believe that access to technology can be beneficial for older adults?] ...[T]otally, because even today there are people who like to queue for electricity [or go to the] bank to pay a bill because, you know...they socialize and, well, they have something to do. But [doing] everything on the phone make[s] it easier...Why go to the bank if I can do it all from home?</p>
Sex life	<p>Well, [I] look at Scruff, obviously, because people see that as spaces for sexual encounters, and the truth is that 80 percent of the time, yes. Worse, I have met people there who have simply become friends and they are not necessarily 2, people with whom I have had sex. I really like Scruff because it is a slightly more adult audience and they have a lot of prevention information and in the profile particularly that you... do not have to disclose your condition, but you can. They even make you a reminder that, if you were screened, you put in the</p>

Themes	Sample Quotes
	<p>last date screened...And they mark you, they tell me, three months go by, they tell me, [if] you have a positive diagnosis, contact your doctor... [I]t is an excellent platform that promotes everything, even activities and meetings, [and] other educational issues and they have a lot of prevention information. Well, look...I don't get into Grindr or anything like that. I even don't know how to open an account on Grindr. But yes, I get into Badoo, through I have also met quite a few gay men on Facebook, including, I have met a lot of gay men in India. I did not know that in India there was such an open community, because obviously India is a subcontinent, a huge country, where I am in a fairly conservative place. But there are other places in India where people are doing things and where there are very activist gay men creating gay groups.</p>
Social support	<p>Support groups...we are here, there is a communal...center or some kind, for example, through the same plans doctors. [They] send some type of communication, literature, that the person...can understand. [It's] easy to see, large print, illustrations. And the person can say: well, look at this application of x things, because the expert can make [it] understandable. ... Because right now you go to a phone company and they put a Samsung phone in your hands. I have a lot of people with Samsung... and they say: wow, this phone works, it's good, it's big, it has three camera. And it's big, but when they take it home they don't think about it, they don't mess with it...they tell the nephew or the baby or the grandson to help them with the phone.</p>
Source of information	<p>OK. It is difficult for me, right now, to search for information about certain things on the internet. And looking for the phones of the sites, everything is a... lot of work for me, you know. I can get in, but it's a lot of work [Participant 11]</p>
Telehealth	<p>They have an application that I have on my phone called Hello... and they send you communications, knowing the medications you are taking. You enter that application and you see the medications you are taking, you see the medical appointments. They send you emails as in feedback on how the services were.</p>

Themes	Sample Quotes
	<p>To that extent, yes: how do you not have to have some knowledge of technology to be able to enter there.</p> <p>Well, I have had calls for medical follow-up over the phone. Not through the camera, but over the phone. I have had follow-up for my appointments, because, in my case, since I am not a patient with other conditions, the reality is that the doctor... has been able to tell me about my results by phone, tell me how they are, make me recommendations, etcetera, etcetera. And I have been able to do it over the phone [Participant 10].</p> <p>[I]f there is something that is related to my health... having a computer helps you to recognize or know more about that new product that is on the market that can be beneficial for you... You search and do research and knowing and having a computer helps you do that, it helps you do that research.</p> <p>[It went] well, very well...The conversation took place as if we were present.</p> <p>[F]or a long period I had to be with appointments like that over the phone. But they were, it was very good...because, from the comfort of home, not having to go to the clinic, not having to get up early to take public transportation and get to the clinic, it was all by phone. So, it...made everything easier.</p> <p>I have used telemedicine services, and when I was with the psychoanalyst in particular, I kept adhering to my therapy every week.</p>
To be in touch with family and Friends	<p>To keep in touch with my family, my friends from high school, we always communicate around there. But it is more to communicate and be more up to date.</p>

Themes	Sample Quotes
	Well, I don't have a very good relationship with my family. Let's start there. So, with my family, I don't communicate with many people in my family, even with almost no one. And I don't know if that's right or wrong, but, well, I don't. But with my friends because through the phone, with India, the video cameras...I have friends there that I talk to. The girl who is helping me now to do the designs there, which is a wonderful woman, I talk a lot with her on camera. And, well, I think that I am more in contact with people who live on the other side of the world than with people who are here close to me.
Use to communicate	I use it to call, for text messages, for Google, sometimes. I read Google, for my music that is all recorded here. I sit down, I put the Bluetooth, oh, beautiful, to hear beautiful music, my music.
Various uses	Well, I use my phone...for meetings, to communicate with my family, with agencies, friends, meeting schedules. And the tablet is also the same. The only thing [is] that in the tablet I do not make calls. You can call by Messenger, but I do not, I have not seen the need. And it is the only thing I basically know how to do, Facebook, WhatsApp and Messenger.

Qualitative responses: Training

Respondents expressed the need for training or workshops on a variety of topics including mental health, housing issues, and technology. They also want to learn ways in which people living with HIV can be more involved in research. Additionally, they call for a training of providers on issues related to the LGBT community, sexual identity, and gender identity.

Table 8

Themes	Sample Quotes
Diverse training needs	I think they help us even more... they could improve... the services, make this contribution of housing, of the services we receive in other places. And maybe even the same in technology, if at some point they have some computer classes or have alternative therapies... that can help us physically and mentally...As there are

Themes	Sample Quotes
	<p>different studies, [like] this one... they need HIV people. Like now, for example, this questionnaire... we can help you and how you encourage us or help ...we can help each other.</p> <p>[Interviewer: What kind of assistance would you need to become a better user of online services?] Training. Training, that is the basis. Training, because what is the use of knowing how to turn on a computer... if you do not know how to use it; it is nothing.</p>
Recommends training providers in LGBT+ issues	<p>All the clinics must... train their staff on the issue of gender identity, on the issue of sexual orientation, from where the office goes and opens, the receptionist, the one who attends the parking lot, everyone. They should have access to that information in detail. Why? Because, then, it makes them a matter of convictions, not of learned scripts; not when you see ¹², you say this, when Zutana comes, you ... No, no, no, it's not that you tell her this or that thing...Where is the educational process of these people? That new employee they got...because they needed a receptionist...How did they guide her? Did you sit down with that person to give him a training on gender identity, on HIV, on negotiation, on safer sex, on what is sex work, on non-discrimination, on not judging? Did they give you training on that before you sat him down at a desk?</p>
Expressing the need for training and technical assistance	<p>Maybe like some classes, right, about that precisely, how to know more about the different applications that there are, how to enter them, like some little classes like that on technology.</p> <p>Well, how to hook her up, teach technology classes. Like to provide more security to one...that he feels confident and that fear of technology goes away.</p>

¹² *Fulana* and *Zutana* is used to speak of someone without saying their name.

CONCLUSIONS AND RECOMMENDATIONS

At the beginning of this needs assessment, we called attention to a well-known psychological tenet: if the most basic of the individual are not fulfilled, other higher-level needs cannot be satisfied. A significant number of our participants stated their need food and shelter.

Individuals¹³ in this needs assessment represent close to a quarter of all LGBT+ people aged 50 and over living with HIV in Puerto Rico. In the survey and interviews, they expressed their

“Human needs arrange themselves in hierarchies of pre-potency. That is to say, the appearance of one need usually rests on the prior satisfaction of another, more pre-potent need. Man is a perpetually wanting animal. Also, no need or drive can be treated as if it were isolated or discrete; every drive is related to the state of satisfaction or dissatisfaction of other drives.”

— Abraham Maslow

health perceptions and needs, barriers to accessing care, and recognized strengths of the health care system.

Respondents, being HIV positive, are, quite literally, survivors. They have endured a disease that once was considered fatal. To do so, they have had to learn how to navigate the health care system, to cope with decades of social insults in the form of homophobia, and stigma.¹⁴

Many also serve as champions and fierce advocates of younger LGBT+ folks. Unlike their counterparts in the mainland (Latino older adults living with HIV), the respondents are highly educated (graduates and

postgraduates); do not experience service barriers due to lack of health insurance, language impediments, or blatant discrimination; nor do they report experiencing the feeling of otherness in encounters with providers lacking in cultural humility.

Most respondents have yet to experience the maladies accompanying old age. They are, as a group, technologically literate, almost uniformly owning smartphones, and they are able to use its basic functions such as texting and searching the web. In addition, the majority have participated in telemedicine calls with their providers. Most of those interviewed are quite

¹³ The terms “individual” or “person” are used interchangeably to refer to the respondent. The intention is to nudge the reader to interpret the findings from the perspective of the affected. We will also use they as a singular pronoun to include the diverse array of gender identification and sexual orientations included in the sample

¹⁴ https://es.wikipedia.org/wiki/Anexo:Terremotos_en_Puerto_Rico

proficient navigating the ever-changing health care system. They have tried different providers until they found the one they are satisfied with. Professional care and personal attention and the sense of “family” created by the providers are chief contributors to their satisfaction.

Despite these strengths, participants need medical, mental health, complementary and alternative services and, in many cases, are not able to obtain them. Despite their education, they often cannot escape poverty. They report feeling lonely and isolated, lacking a partner/spouse and with no children. A significant number experience food and housing insecurity. The testimonies collected highlight the many instances in which they suffer financial hardships either for losing a home to the earthquakes or hurricanes or losing their employment or business to Covid-19. Some are still taking care of their aging parents.

Taken as a whole, the data paint a picture of people in distress, frequently manifested in depression, anxiety, and social isolation. This picture, however, needs to be understood within the frame of the respondents’ life contexts and experiences, which are marked by severe and ongoing trauma and an inability to access services and resources to ameliorate it. Advocacy leaders and treatment providers in Puerto Rico have been calling attention to this situation for a long time, and the findings of this needs assessment validates their concerns.

Many LGBT+ ~~men~~ individuals aged 50 and above living with HIV in Puerto Rico have experienced numerous traumatic events, including: 1) the diagnosis of, what, at the time, was a mortal disease; 2) the day to day challenges of coping with this dreaded disease; 3) dealing with the toxic experience of homo/transphobia and stigma ; 4) the Zika epidemic; 5) two Category 5 Hurricanes; 6) nine major earthquakes since 2014,¹⁵ followed by over nine thousand aftershocks; 7) the Covid epidemic and the accompanying economic decline and social isolation; 8) the political turmoil which resulted in the resignation of the Governor in 2019; 9) a declining economy; and 10) one of the largest migration to the mainland United States since the 1950’s It is estimated that these events resulted in the loss of up to one 11.8% of the Island population.¹⁶

¹⁵ <https://disasterphilanthropy.org/disaster/puerto-rico-earthquakes/>

¹⁶ <https://www.nbcnews.com/news/latino/puerto-ricos-population-fell-118-33-million-census-shows-rcna767>

The scientific evidence has long identified the association between trauma and distress, both in the general population and the LGBT+ population in particular. This distress stems from force majeure—earthquake, hurricanes, and epidemics—as well as the traumatic effects of everyday bias and stigma. As such, these individuals require interventions that are trauma informed. A trauma-informed approach encourages service providers to recognize and address the presence and impact of traumatic events on a patient and mobilize the necessary resources to address them.

What actions can be taken by advocates and policymakers to help improve the mental health and well-being of older LGBT+ ~~men~~ individuals in Puerto Rico with HIV? A strategic way to address this question is to approach the problem from a health-systems perspective. We have already described the individuals at the center of the system. This is followed by the relation of these individuals to other immediate life contexts such as family, work, social activities, and the health care system. Distal contexts such as the public policy arena that guide the delivery of services were not the direct subject of this need assessment. However, we will use the findings of this assessment to identify opportunities that exist within those distal contexts and to make recommendations that can improve the existing system of care.

Challenges and opportunities

Family

The family remains an important referent in the lives of older LGBT+ ~~men~~ individuals living with HIV in Puerto Rico. For those still taking care of their aging parents, the family context is their *raison d'être*. They organize their lives around caretaking activities and worry constantly about infecting aging parents with Covid-19. They are afraid of infecting their family members due to the day-to-day experience of traveling to visit them, shopping for groceries, or obtaining health services, making caring for ageing parents an ongoing challenge.

The family concept also serves as a metaphor to explain participants' satisfaction with services. Those who are satisfied with their services often frame their reason or rationale for that satisfaction in terms of the family, noting that, “Me siento como en familia,”-- “It feels like

family.” They seem to project onto the healthcare team the feelings, perceptions, and emotions they hold towards the family. This emphasis on the family seems to be a cultural tool that providers can build upon, integrating it as a strategy to engage and retain these individuals in care.

Social Isolation

Even before the arrival of COVID-19, social isolation affected the lives of older adults in general, particularly those who identify as LGBT+. Covid-19 has worsened the situation. While most of the participants use social media to reach out to relatives and friends or to seek sexual partners, the data didn’t show evidence of a strategy purposefully created to increase social connectedness. Since most participants have basic digital literacy and have access to a smartphone, a social media intervention could be a strategic way to mitigate the deleterious impact of loneliness.

Systems and Services

The existing system of care that address the medical, mental, and social needs of the older LGBT+ population is one that, at the provider level, is strong. Participants are satisfied with health services where providers show respect, are caring, to provide comprehensive care, and makes them feel comfortable. Yet significant operational and structural components of the health care system need improvement, particularly those related to accessing care. Participants reported being dissatisfied with the many barriers they encounter accessing service, such as transportation, the appointment system, waiting times, and not knowing whether or not a service is available. They also showed a strong interest in complementary and alternative services, but, unfortunately, they experience difficulties obtaining them.

Recommendations

Given what we know about the state of older LGBT+ ~~men~~ individuals living with HIV in Puerto Rico, what specifically can be done to improve their life situation?

First, policymakers should recognize that, for the most part, members of this population obtain their services in a system of care that was designed for the cis-gender heterosexual population. Some respondents report experiencing HIV, gender, and age discrimination. Through their advocacy, assertiveness, and persistence, the respondents have been able to nudge the system to align service delivery with their needs as LGBT+ individuals. However, these efforts have not been more comprehensively successful. Changes to the types and availability of services, as well as the accessibility to a variety of services needs to begin with policymakers, management, and funders.

Second, the strengths of this population should be recognized, celebrated, and activated. Previously we alluded to some of those strengths (resiliency, assertiveness, and high levels of education). There is rich intellectual capital within this community. About 27.5% have completed a Bachelor's degree, 22% a Masters and 6% a Doctorate degree. To illustrate, this community assessment was created by researchers, thought leaders and staff that are themselves members or allies of the LGBT+ community.

Third, there is a need to increase accessibility to all existing services, those within the Ryan White Care funded services and those outside of this network of funded services but that are providing services to the LGBT+ and older individual. We encourage a creative and flexible conceptualization of "accessibility." Thus, we encourage policymakers and service providers to strengthen the use of social media and mobile services; modify existing services to make them more LGBT+ inclusive; involve people with lived experiences as members of the LGBT+ community in service delivery; conduct diversity, equity, and inclusion audits; and devise other creative solutions "outside of the box," while using science-based interventions to improve those services that are already in place. For instance, the anxiety and distress caused by housing and food insecurity can be mitigated if at-risk individuals were made aware of resources and opportunities to deal with such challenges. Community support services such as legal services, LGBT+ social events, and housing and aging services mitigate social isolation and might reduce the demands on mental health services. Complementary and Alternative Medicine (CAM) services, in turn, may amplify the impact of traditional medical services and improve quality of life. CAM services are highly valued by the individuals and not expensive to implement. Many

of these services focused on the LGBT+ aging community are currently offered in Puerto Rico, but transportation challenges and publicity deficits render these services under-utilized.

Fourth, while most of the participants were digitally literate, they wanted more training and capacity development services in the use of technology. Since technology is ever-changing, programs for upgrading devices should be considered. Social media can be an effective way of addressing isolation, to creating community, and delivering services. In fact, one participant referred to Facebook as the “psychologist of the poor.” Social media can also raise awareness of existing services and enhance accessibility to services.

Fifth, the participants reflect a diverse segment of the older LGBT+ community who are veterans of living with HIV, trying to live to their full potential. Public servants, elected officials, public health advocates, providers, and community members-at-large should read these findings as a window to a community that is searching for equity and equality in health-care in their community and in Puerto Rico as whole. Listen, learn, and advocate!

Limitations

This needs assessment has a number of limitations. First, the data was collected during the COVID-19 epidemic, and it is difficult to ascertain whether or not the distress documented in the findings is due to COVID-19 or to already existing causes. Data was collected between late April and June 2021.

Second, we referred to the LGBT+ community as a whole. However, between and within the Lesbian, Gay, Bisexual and Transgender community, and the myriad sexual orientations denoted by the “+” symbol there are unique needs, differences, strengths, and views. Due to budgetary limitations these issues were not attended in this study.

Third, the sample was recruited through social media platforms such as Facebook and Twitter, meaning that the participants are individuals who already know how to access social media. Although some surveys were collected in person, the COVID situation in Puerto Rico at the time impeded us in continuing in this format; hence, we changed all activities to web based.

Fourth, we were not able to obtain permission to recruit in the OCASET (Oficina Central para Asuntos del SIDA y Enfermedades Transmisibles)¹⁷ clinics because the research team was not able to secure the required permissions rendered by the Department of Health within the contractual timeline. In addition, the unit in the Department of Health focused on this population and supervising such clinics has been in the planning phase of conducting a similar study among all of the constituents living with HIV in Puerto Rico for the last few years. At time of writing this report, they announced that they are planning to begin sometime in early 2022.

Fifth, the sample was a non-probability sample; thus, the findings are not generalizable to the broader population. This cohort represents “very young older adults”; that is, participants as young as 50-years of age. As such, they did not express the need for assistance in performing activities of daily living typically reported by their cis-heterosexual counterparts. That selection was purposefully determined, for the sponsors of this needs assessment wanted to gather evidence to assist in the implementation of early prevention strategies to address the service barriers experience by older adults living with HIV.

¹⁷ Central Office for AIDS and Communicable Disease

Acknowledgements

SAGE -The national advocacy and services organization that's been advocating and providing services with and on behalf of LGBT elders since 1978. Through SAGE network of 29 affiliates, stands proudly with the LGBT pioneers across the country who've been fighting for decades for their right to live with dignity and respect.

Website: <https://www.sageusa.org/>

WAVES AHEAD CORP, the leading 501c3 community-based organization in Puerto Rico offering supports to marginalized and vulnerable sectors of society by giving them the necessary **help to strengthen their community and family environment.** Waves Ahead Corp manages *SAGE Puerto Rico* and its LGBT+ Senior Community Centers across the island. **SAGE Puerto Rico** is an affiliate of SAGE, which provides advocacy and services for the LGBT+ older adults.

Website: <https://wavesahead.org/>

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JSI Research and Training Institute, Inc. was founded in 1978 and is a 501(c)3 nonprofit health care research and consulting organization with headquarters in Boston, Massachusetts (MA). JSI has a staff of more than 400 with expertise in public health and research methods, and

has been working with the Health Resources and Services Administration (HRSA) HIV/AIDS Bureau (HAB) and Ryan White HIV/AIDS Program (RWHAP) recipients since the Program's inception 31 years ago. JSI has also worked in all 50 states, Puerto Rico and in more than 40 other countries providing technical assistance (TA), training, needs assessments, community planning, program evaluation, data analysis, quality improvement (QI) programs, and health systems transformation initiatives.

Website: <https://www.jsi.com/>

Alexia Consulting LLC- Founded in 2020 by Alexandra M. Bonnet, MSW a Cisgender woman with a master's degree Magna-Cum-Laude in Social Work in the advanced program, specializing in Administration and Supervision of Human Services Agencies at the Universidad Interamericana Metropolitan Campus, Puerto Rico (2010), and Independent Consultant. With more than 10 years of experience working with Public Health, specifically with topics such as; prevention of sexually transmitted infections, HIV, sexuality, and diverse communities, including the communities of women, men, youth and LGBTTIQ +, *Alexia Consulting LLC* specializes in working with organizations that want to implement human services programs. By offering independent consulting in the pre-implementation, implementation, adaptation, monitoring, evaluation, and maintenance phases of the programs, including how to implement *Evidence Base Interventions* (EBI) and locally developed interventions she guides agencies in to exceeding their goals and objectives. As a Consultant Alexandra has offered services to JSI with the following projects:

- *VWIEC from Hampton University* with the evaluation of their incubator program and translation activities,
- *Waves Ahead Corp & SAGE Puerto Rico*, with the LGBTTIQ+ HIV positive 50 plus needs assessment
- *Neighbor to Neighbor Springfield MA*, with their program Gambling program among other consulting activities.

Alexandra has worked with translation services (English to Spanish and vice versa) and consulted on the cultural and linguistic aspects of the implementation of programs.

Alexia Consulting, LLC has also worked with grant writing for:

- The CDC with AccessMatters from Philadelphia
- *Waves Ahead Corp & SAGE Puerto Rico* and other local agencies in Puerto Rico.

Overall, as an Independent Consultant she has provided consultation to senior staff and clients in the design and implementation of health data reporting systems and strategies. The achievements of her work have been presented in the USCA at a national level between the years 2012-2019.

Landing page: <https://linktr.ee/alexiaconsulting>

A health needs assessment of the LGBT+ community, aged 50+, living with HIV in Puerto Rico.



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