

UBUNTU-PAMOJA COMMUNITY REPORT

Ubuntu-Pamoja Study:
Enhancing HIV and STBI
Testing and Care for African,
Caribbean and Black
Communities in Manitoba

Bolaji Akinyele-Akanbi, Chinyere Njeze, Patricia Ukoli, Dorcas Kwarteng, Rusty Souleymanov, Deborah Balogun, Shemar Barnes, Tracy-Ann Campbell, Mohamed Mohamed, Magalie Sibomana, Nadine Tshite, Judy Williams, Justine Zidona, Wangari Tharao, John Kim, Paula Migliardi, Ayn Wilcox, Mike Payne, Laurie Ringaert, Linda Larcombe, Gayle Restall, Robert Lorway, Nathan Lachowsky, Haran Vijayanathan.

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Land Acknowledgement

This project took place on the traditional lands of the Indigenous Peoples of Turtle Island, including the ancestral territories of the Anishinaabeg, Cree, Oji-Cree, Ojibwe, Dakota, and Dene peoples, as well as the homeland of the Red River Métis Nation. We acknowledge and appreciate the ongoing resilience and resistance of the Indigenous and Afro-Indigenous Peoples across Turtle Island in the face of colonial violence as they strive for self-determination and decolonial futures. The African, Caribbean, and Black (ACB) communities honor the memory of our ancestors who experienced forced displacement and trafficking to Turtle Island as a result of the Trans-Atlantic Slave Trade, as well as those who migrated to these lands in this generation or earlier generations. We recognize the impact of racial and colonial violence on ACB, Indigenous, and Afro-Indigenous Peoples and affirm our commitment to standing in solidarity with Indigenous communities in the process of truth and reconciliation, understanding the importance of being respectful guests on these lands.

Foreword

The process of migration involves moving from the known to the unknown. Therefore, regardless of the push or pull factors, migration impacts not only the physical, mental, sexual, and spiritual well-being of individuals and communities but also disrupts socio-cultural aspects. These disruptions can affect cultural identity, social cohesion, and community dynamics, further influencing overall well-being^{1,2}. Although lack of access to health care and information on HIV (Human Immunodeficiency Virus) and STBBI (Sexually Transmitted Blood Borne Infections) may influence the health-seeking behavior of African and Caribbean immigrants and refugees, stigma, isolation, and systemic racism also deter Black people from accessing HIV/STBBI services^{3,4}. In 2020, our team's pilot project, called the Migration and Health Study (funded by CIHR), highlighted the systemic gaps and concerns of stigma, racism, and the lack of culturally appropriate HIV/STBBI services faced by African, Caribbean, and Black communities. These factors, along with other personal factors, exacerbate HIV/STBBI disparities among Black communities in Canada, especially in Manitoba, where we have the second-highest number of new HIV/STBBI diagnoses^{5,6}. In response to the urgent need for HIV/STBBI prevention and treatment and the scarcity of community-based participatory studies on HIV/STBBI among the ACB communities in Manitoba, we developed a three-year mixed-methods community-based participatory study called the “Ubuntu-Pamoja Study” (also funded by CIHR).

Objectives of the Ubuntu-Pamoja Study:

- Understand the acceptability of different types of HIV/STBBI testing.
- Build capacity within the community.
- Create linkages to care services.

Key Findings of the Ubuntu-Pamoja Study:

- ACB participants spoke of communities' distrust of the healthcare system.
- Participants expressed ethical concerns about the use of ACB healthcare information and HIV biomaterials.
- The need for multiple testing options, with some participants preferring self-testing at home and others opting for community clinics for point-of-care or dried-blood testing.
- The lack of testing clinics in rural areas was identified as a barrier to accessing HIV/STBBI testing.
- Community engagement and empowerment were seen as successful strategies to address HIV/STBBI prevention and testing acceptability among ACB community members.

Acknowledgements

The Ubuntu-Pamoja research team would like to thank the African, Caribbean, and Black community members who participated in this study and shared their knowledge, experience, and wisdom. Your perspectives, experiences, and expertise have tremendous value. We hope to do justice to your voices and perspectives throughout this report. The authors would also like to thank everyone who worked with us to develop the research and this report. We acknowledge the research team members, including Wangari Tharao, Robert Lorway, Ayn Wilcox, John Kim, Laurie Ringaert, Linda Larcombe, Mike Payne, Gayle Restall, Haran Vijayanathan, Nathan Lachowsky, Paula Migliardi, and Marco Sousa.

We want to acknowledge the following research core team who worked on the Ubuntu Pamoja Study: **Rusty Souleymanov, Bolaji Akinyele-Akanbi, Chinyere Njeze, Dorcas Kwarteng, and Patricia Ukoli.** We would also like to thank the **Community Guiding Circle (CGC) members (Deborah Balogun, Judy Williams, Justine Zidona, Magalie Sibomana, Mohamed Mohamed, Nadine Tshite, Shemar Barnes, Tracy-Ann Campbell)** who worked with us to inform and strengthen this research initiative.

We are honoured by your contributions and your leadership in informing and guiding our work. We would like to sincerely thank the HIV/AIDS and sexual health community organizations that worked with our team throughout this research project – Public Health Agency of Canada, Nine Circles Community Health Centre, Klinik Community Health, Women's Health in Women's Hands – Toronto, Manitoba HIV-STBBI Collective Impact Network, the Winnipeg Regional Health Authority, and academic partners at the University of Manitoba and the University of Victoria.

Finally, we are grateful to the Canadian Institutes for Health Research and the Faculty of Social Work at the University of Manitoba for their financial support of this initiative.



Terms / Glossary

STBBI: Sexually transmitted and blood-borne infections (STBBI) is an infection that can be transmitted from one person to another through the exchange of semen, vaginal fluid, blood, or other body fluids, during sexual contact, including oral sex or contact with any of these body fluids.

HIV: HIV is a virus that weakens your immune system, which is your body's built-in defence against disease and illness. It can be transmitted through sexual contact with infected blood and from mother to child.

DBS: Dried blood spot (DBS) testing is a method of blood collection that can be used for diagnosing hepatitis C, HIV, and other STBBI.

PHLEBOTOMY: The process of obtaining blood from the vein using a needle. The blood drawn is used for analysis or diagnosis.

POST-TEST COUNSELLING: This counselling is done after the test has been done. It provides information about prevention, diagnosis management, treatment, and coping skills.

PEER NAVIGATORS: Peer navigators are members of the African, Caribbean, and Black communities trained to support participants who have indicated interest or consented to participate in the study.

ACB: ACB refers to people from African, Caribbean, and Black communities.

CBR: Community-based research is research led by the community in partnership with other stakeholders (students, faculty, funders) and community agencies.

CGC: The Community Guiding Circle consists of 10 members of the ACB communities who will guide the study's implementation.

2SLGBTQIA+: **LGBTQIA+:** Is an abbreviation for Two Spirit, lesbian, gay, bisexual, transgender, queer or questioning, intersex, asexual, and more. These terms describe a person's sexual orientation or gender identity.

Executive Summary.

The Ubuntu-Pamoja study was conducted to understand the experiences and perspectives of African, Caribbean, and Black (ACB) communities in Manitoba regarding HIV and STBBI testing. This collaborative project involved the Community Guiding Circle (CGC), a group of 13 ACB community members, to guide the research process. Recruitment targeted ACB individuals aged 18 and older living in Manitoba through community agencies, social media, and flyers. Data collection included qualitative consultation interviews, a cross-sectional online survey, and post-test interviews. The study enrolled 33 participants for consultation interviews, 351 for online surveys, and 10 for post-test interviews. Participants ranged from 18 to 50 years old, with diverse gender identities, sexual orientations, and educational backgrounds. The majority lived in Winnipeg, Steinbach, and Brandon, with varied immigration statuses and employment situations. Consultation interview participants expressed significant concerns about the collection, sharing, and use of HIV data, highlighting mistrust towards institutions like police, child welfare, and immigration. Issues included data misuse, potential human rights violations, and privacy concerns. Participants required greater transparency, informed consent, and control over their health data.

The provincial survey with 351 participants explored preferences for different testing methods and identified demographic factors associated with HIV testing history, including age, employment status, education level, sexual orientation, gender identity, and immigration status. The survey also revealed that home HIV self-sampling was preferred for its convenience and privacy, while clinic-based dried blood spot testing was chosen for its comprehensiveness (testing for multiple STBBIs). Post-testing interviews highlighted that while participants chose self-tests for convenience, privacy, and confidentiality, many faced challenges with instructions and blood sample collection.

The findings underline the complexities of HIV testing within ACB communities, particularly ethical considerations. The study also highlighted the feasibility of HIV self-testing and clinic-based dried-blood spot testing to engage ACB communities and address knowledge gaps. Continuous exploration of health needs and outcomes within these communities is essential. Service providers, advocates, and policymakers should expand the availability of take-home HIV self-testing kits and explore other types of HIV/STBBI testing strategies. They need to strengthen support for healthcare services at community events and local health centers, addressing gaps in healthcare access and testing among ACB communities. Increasing educational efforts around HIV/STBBI testing, providing clear instructions for self-tests, and implementing comprehensive sexual health education programs are essential steps. Communicating the safety of these testing methods and offering robust support systems is also crucial. This means ensuring that the testing procedures are physically safe, respecting privacy and confidentiality, and providing culturally sensitive support to address any concerns or fears individuals may have about the testing process. Health promotion campaigns should be tailored to specific demographics to maximize reach and effectiveness. The Ubuntu-Pamoja study's insights into HIV and STBBI testing among African, Caribbean and Black communities in Manitoba underscore the importance of culturally sensitive, transparent, and ethical healthcare practices. By implementing the study's recommendations, we can work towards improving health outcomes, fostering trust and relationships, and ultimately creating a more equitable and effective health system for all African, Caribbean and Black people in Manitoba.

Introduction

African, Caribbean and Black migrants (including newcomers, immigrants, refugees, and people without resident status) remain overrepresented among new human immunodeficiency virus (HIV) and sexually transmitted and blood-borne infection (STBBI) cases in Manitoba 7,8. Community-based Research (CBR) among African, Caribbean and Black migrant communities in Manitoba is inadequate particularly on issues regarding sexual health, living with HIV and HIV/STBBI-related health system access and navigation. Our exploratory pilot study showed the health system gaps and issues that these communities face, including access barriers, experiences of racism in healthcare, stigma, lack of culturally specific health education and HIV/STBBI prevention. These factors have been identified as potentially worsening the already rising rates of HIV/STBBI cases among African, Caribbean and Black communities and their social networks 9,10,11,12.

Even though there are advancements in knowledge, very little is known about the factors that shape HIV/STBBI risks for African, Caribbean and Black communities in Manitoba, particularly those who come from countries where HIV is widespread. Importantly, almost nothing is known about HIV/STBBI testing practices and the suitability of Self-testing and Dried Blood Spot (DBS) testing among African, Caribbean and Black migrant communities in Manitoba. There is an urgent need to understand the use of self-testing and DBS testing practices and how this population is affected by HIV/STBBI in Manitoba. Despite the gap in knowledge in this area, historically there are also limited CBR capacity-building opportunities available for African Caribbean and Black communities in Manitoba. This project will enhance these gaps in knowledge and build capacity among community stakeholders in Manitoba. The Ubuntu Pamoja study, coined from an African term (Swahili), wherein 'Ubuntu' means humanity to everyone while Pamoja denotes togetherness.

Contextualizing Ubuntu-Pamoja Study: Decolonizing Approach

Ubuntu is an African philosophy that emphasizes communal values, human dignity, and social cohesion, encapsulated in the phrase "I am because of who we all are." It is rooted in the principles of humanism and promotes human rights, sharing, collaboration, and social justice. Ubuntu is a humanistic-existential approach in social work, which highlights themes such as self-awareness, self-determination, holism, and the pursuit of social justice¹³. According to some of the findings from the focus group discussions, Ubuntu and Pamoja underpin the community-centric lifestyle of many African, Caribbean and Black communities, advocating for co-responsibility and the sharing of human values. A study on the interconnectedness of self and community within Ubuntu, emphasizes reciprocity and mutual recognition as foundational to this ideology^{14, 15}. This philosophy also informs practical approaches, such as HIV prevention and communal problem-solving, by fostering a sense of identity and community solidarity, reflecting the inherent communal consciousness prevalent in African, Caribbean and Black cultures.

The community members emphasized the concept of "Pamoja," which they associate closely with togetherness and unity within the community's diversity. They described how this notion facilitates a comprehensive understanding of community dynamics and issues, thereby allowing for more ethical and equitable interventions. The integration of Pamoja in community-based research was seen as essential for representing and addressing the community as a collective entity. Additionally, participants reflected on "Ubuntu," a philosophy they related to growing up in their home communities where individual actions were always considered in the context of their impact on the community at large. This perspective fosters a deep sense of connectedness and responsibility, guiding community members to act cautiously and considerately.

For example, one community member articulated the essence of "Pamoja" as follows: *"So, for me, the concept of Pamoja is togetherness. When we think about communities, there are so many different aspects that make up a community. And doing research in a community, I think the concept of Pamoja just brings it forward in the best sense ever. Because we are coming together, and it is a representation of the community as a whole in terms of its diverse nature, to assess what is actually impacting or going on within our community to then be able to address it more ethically and equitably."* This perspective underscores the role of Pamoja in fostering unity and facilitating a deeper understanding of community issues for more effective interventions. Reflecting on "Ubuntu," another participant shared: *"For me, the concept of Ubuntu, when I think about it, takes me back to growing up back home. What we've been taught is when you are living you are living for the community. So, it's not about you as an individual. It's about how your actions affect the whole community. So, it kind of brings our mind to think about being very cautious of our actions and that connectedness. Also, when I think about Pamoja, which reflects togetherness, I see this Ubuntu-Pamoja as kind of intertwined because we are very much conscious of what we are doing or the action and the impact on others and working with others for the benefit or for the betterment of your community."*

Another individual emphasized the communal ethos prevalent in ACB communities: *"I feel like most ACB communities already have this, so we are communal people. It's not just for ourselves. So, it's just creating that awareness of existing programs, and I believe our community would embrace it. So, I think the approach to HIV testing has been more individualistic and we are not an individual kind of community. We are more communal. A communal approach works better for us. So, I think that is a shift that needs to happen in terms of HIV testing. We also need to take advantage of existing community events." This highlights the preference for communal strategies in health interventions, aligning with the intrinsic values of the community. Linking these concepts, the community described how Ubuntu and Pamoja naturally intertwine, enhancing consciousness about individual actions and their broader impacts. This collective awareness is pivotal in fostering cooperation and collective action for the betterment of the community."*

Community Partners

The project was a collective project involving several community partners: Nine Circles Community Health Centre, Klinik Community Health, Manitoba HIV-STBBI Collective Impact Network, Manitoba Harm Reduction Network, Mount Carmel Clinic, Nor West Co-Op Community Health Centre, Women's Health in Women's Hands, the Public Health Agency of Canada, the Winnipeg Regional Health Authority, and the University of Manitoba.

The three-year exploratory sequential mixed-methods research study aimed to bring together a regional leader of experts (community members, researchers, public health practitioners, community-based organizations, policymakers, and municipal and provincial governments) to implement innovative community-based research and peer-led intervention in HIV/Sexually Transmitted Blood Borne Infections (STBBI) DBS, self, and point of care testing.

How We Conducted the Study

The research team formed a Community Guiding Circle (CGC), made up of 13 members of African, Caribbean, and Black community members working in different health and social organizations in Manitoba. Along with the core research team, the CGC met at least five times per year online to provide guidance and advice on the research process, recruitment, and implementation of the study. The CGC provided meaningful and extensive input throughout the study. This collaborative approach between researchers and the CGC enriched the study's design and outcomes. This project also required six weeks of training for peer navigators, ongoing meetings with stakeholders, and a larger research team. The core team (Bolaji Akinyele, Chinyere Njeze, Patricia Ukoli, and Rusty Souleymanov) implemented various aspects of the project.

Ethics

The study received ethics approval from the University of Manitoba Research Ethics Board (# HE2022-0264) in 2021. All methods were carried out in accordance with relevant guidelines and standards. Likewise, all participants provided informed written consent, and their data were kept confidential.

Recruitment and Eligibility

We recruited a diverse sample of participants through community agencies, social media, and flyers, with considerations for variations in age, gender, sexual orientation, and geographical location. Eligibility included: 1) identify as African, Caribbean or Black; 2) be 18 years of age or older; and 3) be living in Manitoba. The flyers are presented below.

Data Collection and Analysis

Data collection occurred in three phases: consultation interviews and, consequently, the online survey and post-testing interviews. We utilized both qualitative and quantitative methods of data collection. Participants participated in 45–90 minutes qualitative consultation interviews that sought their input and preferences on testing procedures in Manitoba. This was followed by a 30-minute cross-sectional, province-wide, multi-mode survey (online, phone, and mail-in versions) and a one-hour post-test interview for those participants who consented to take part in post-test interviews. For the post-testing interviews, which was a follow-up to the survey, questions explored participants' perspectives and experiences with HIV and STBBIs testing, including access to HIV testing. Questions also sought participants' experience with confirmatory testing, if applicable, the care received, uptake of referrals and experiences with peer navigators/ testers.

Participants received \$40 compensation for the interviews and \$25 for the survey. For the quantitative component, we conducted descriptive analysis of the data. For the qualitative component, the study employed iterative, inductive, and thematic data analysis. To increase the rigor and trustworthiness of the findings, the research team carefully read through all the transcripts, line-by-line, to identify and annotate initial codes based on their interpretation of the text. We identified key themes and patterns in the data through a collaborative process. Four members of the research team also did the analysis and then checked for consistency in two research team meeting discussions and two member-checking meetings with CGC. This helped us make sense of the participants' experiences.

Interview Sample Characteristics

Our study enrolled 33 ACB community members in Manitoba for the consultation interviews, 351 participants for the online surveys, and 10 ACB members for the post-test interviews. The participants for the consultation interview had a mean age of 34, ranging from 18 to 50 years old. Among them, 20 individuals identified as women and 13 as men. In terms of sexual orientation, 25 participants identified as heterosexual, while 8 identified as members of the LGBTQIA+ community. Geographically, most participants lived in Winnipeg and Steinbach. Regarding educational attainment, 27 individuals had some form of university or college education, while six individuals had a high school diploma. Among all participants, 22 were actively employed, 2 were international students, and 3 were unemployed.

The sample represented individuals from diverse backgrounds: 10 from the Caribbean, mainly Jamaica and Trinidad; 18 from various African nations such as Nigeria, Ghana, Sudan, the Congo, the DRC, Burundi, and Kenya; and 5 individuals were born in Canada (with 2 from the Caribbean and 3 from African communities). Immigrants and refugees in the study had lived in Canada for varying lengths of time, with an average of 9.8 years (the range of time spent in Canada varied from six months to 30 years). This report reveals what we learned from the stories and experiences of ACB people in Manitoba in relation to HIV and STBBI testing using dried blood spots, self-tests, and point of care rapid testing.

Interview: Summary of Findings

Participants expressed significant concerns about the collection, sharing, and use of HIV data from healthcare encounters, revealing mistrust towards institutions like police, child welfare, and immigration accessing their health information. Their worries centered on the handling of biological samples, data misuse, potential human rights violations, HIV criminalization, deportations, challenging consent, privacy, and bodily autonomy principles. While open to contributing to medical research, they unanimously requested greater transparency, informed consent, and control over the secondary use of their health data. The study underscores the need for culturally safe approaches in HIV testing and ethical governance in healthcare for ACB communities. It highlights the importance of prioritizing participant empowerment, ensuring transparency, practicing informed consent, and implementing robust data security measures to balance effective HIV information management with the protection of individual rights.

Interview: Main Findings

Participants expressed discomfort with institutions accessing their health data due to concerns about potential misuse and the fear of being criminalized. They highlighted the exploitation of Black communities in medical research, demanding transparency-and control over their information. The need for informed consent, clear communication on blood/biological sample use, and ethical considerations, including compensation for future research use, was emphasized.

Concerns Surrounding Access and Misuse of HIV-Related Information by Institutions

Participants expressed a lack of safety and mistrust towards institutions like police and immigration accessing their health data, dissatisfied with the transparency around sample handling and potential misuse of their HIV test results: "I don't think they provide enough information. They just tell you the basics of why you are doing the tests, and if the result is positive, how you can be linked to care. Nobody really goes into details regarding how your sample travels and who has access to your results... I don't know if they would deny me permanent residency because of my HIV status... They may not give you permanent residency or citizenship." (Participant #03).

Many participants evoked the potential involvement of child and family services, echoing a history of systemic racism faced by ACB communities: "I think that there's a lack of information around this, especially when it comes to immigration, police, and child and family services. Some people might [say], oh, they're going to take my kids away from me. So, they weren't well informed about the process and the consequences of giving samples and the results." (Participant #11).

Another participant evoked a recent HIV criminalization case in the Canadian media about a refugee living with HIV being deported: "Media too, I am recalling an incident that required the deportation of someone who was HIV positive...and people still talk about it today. I think that's a reason to fear." (Participant #21). The fear of personal data associated with test results being shared across multiple institutions and the potential for criminalization contributed to hesitancy among some community members: "Those who suspect they might be HIV-positive don't want to go and do the testing to confirm. If one institution has my result, another institution can check these results... Clinics, hospitals, and other establishments that deal with health issues, communicate...So, in terms of criminalization, how am I going to prove that I am safe when I have my result shared everywhere?" (Participant #07).

Respondents were also worried about the consequences of testing on health insurance: "Community members are concerned because it might affect their health insurance premiums because of the number of bills. I think there will be some concern on the part of community members regarding who has access to their sample and their results..." (Participant #08).

Uncertainty Regarding the Future Use of HIV Data and Bio-samples

The recurring theme among participants in this study was the uncertainty regarding the future use of HIV samples: “I honestly don’t know. I think it would be helpful in one regard in medical advancements. But on the other hand, you don’t have a lot of control or knowledge of what they will be doing with that sample, so I’m unsure.” (Participant #26). Some participants evoked historical discourse on the exploitation of Black communities in medical research and testing: “I think just given the history of testing on Black people and what the outcome of that was, I can see why, you know, Black people are hesitant about it... Also, in the past there have been examples of, you know, that stuff being used against Black people, so I think those concerns are valid.” (41-year-old, Caribbean woman; ID38). Similarly, one participant commented: “Historically, the black community has been used as Guinea pigs for various types of research, so that is still in our memory... I can definitely see concerns from community members with regards to the future use of their own [blood] samples.” (Participant #05). Along these lines, some participants talked about their fears of others exploiting their bio-samples: “I do know there have been instances through history where people do take it upon themselves to exploit our samples, our DNA, and things like that, so I have concerns about the future use of my samples.” (Participant #26).

Some participants were also open to the idea of their health-related information or blood samples being used for further research, reflecting some degree of trust in the medical field. However, concerns about who has access to their test results were voiced by some participants. These concerns primarily revolved around non-medical professionals, such as social workers or public health officers, accessing their information without their consent. Participants expressed a preference for being informed and involved in the decision-making process if access to their information was deemed necessary for non-medical purposes: “I am OK with doctors seeing it in the future, but if, let’s say, a social worker or other public health officers want access to it, for whatever reason then I would like if I was maybe like notified and given the choice of whether or not I would like them to have access to it or not.” (Participant #15).

Another participant highlighted the ethical boundary concerning the future uses of biomaterials: “If what I am giving is going to help more people... maybe used to find a cure, then that is good and ethical. However, if it goes in a negative direction, causing stigma, then I have a lot of issues with that. We have to show this sample won't bring fears, won't stigmatize the community, and won't be a weapon.” (Participant #01).

Similarly, another participant commented: "Is it all destroyed once they give me my results, or what happens with my sample? I would need to see what my results were, and if I personally thought that it would be a help to science, then I'd let them keep my results...Once I've got my results, I'd like to be able to sign something that says either permission to keep this for future research or permission to destroy this right away." (Participant #13).

Participants also stressed the necessity of providing clear information and transparency: "Tell community exactly where the sample is... a path. Even if you have to do a diagram... a picture of where their sample travels. Very straightforward and informative before they agree."

(Participant #22). Some participants also contemplated the potential use of health-related information or samples collected during an HIV test for future research or studies, for example: "When they do this... after maybe... three or four years... will they still come back to tell me? They can use my sample, but I don't want to hear about that after like 10 years" (Participant #06).

Some participants also voiced concerns about the future sale of their information: "I don't want the information to be sold; I don't know where people sell to. Everyone is always paranoid about it getting sold to something. I don't want that. Again, I'm assuming that it [test result] will be treated in an ethical manner." (Participant #25). Lastly, one participant asserted that if researchers were to use their sample in the future, "there should be a consent and probably further compensation" (Participant #19).

Summary of Survey Findings

Findings offer a unique perspective on the community's health practices and needs, providing valuable insights for future public health initiatives and policies aimed at improving the well-being and healthcare accessibility for the African, Caribbean and Black communities in Manitoba.





Demographic Analysis

UBUNTU-PAMOJA STUDY

SURVEY FINDINGS

We conducted a provincial online survey with 351 African and Caribbean community members to learn about preferences for different testing methods. When participating in our online survey, participants had the option to request a take-home HIV self-testing kit, or if desired, request HIV or STBBI testing by a trained healthcare provider.



This infographic provides a unique perspective on the health, *testing practices*, and needs of the community, offering valuable insights for future public health initiatives and policies aimed at enhancing well-being and healthcare accessibility for African and Caribbean communities in Manitoba.

DEMOGRAPHICS

The demographic section of the Ubuntu-Pamoja Survey provides a comprehensive overview of the participants, highlighting diversity in ethnicity, age, employment status, education level, sexual orientation, gender identity, immigration status, and household income.



- Black-African (67.8%)
- Black-Caribbean (32.2%)

Among 351 respondents, 238 (67.8%) identified as "Black - African"; and 113 (32.2%) of respondents chose "Black - Caribbean".



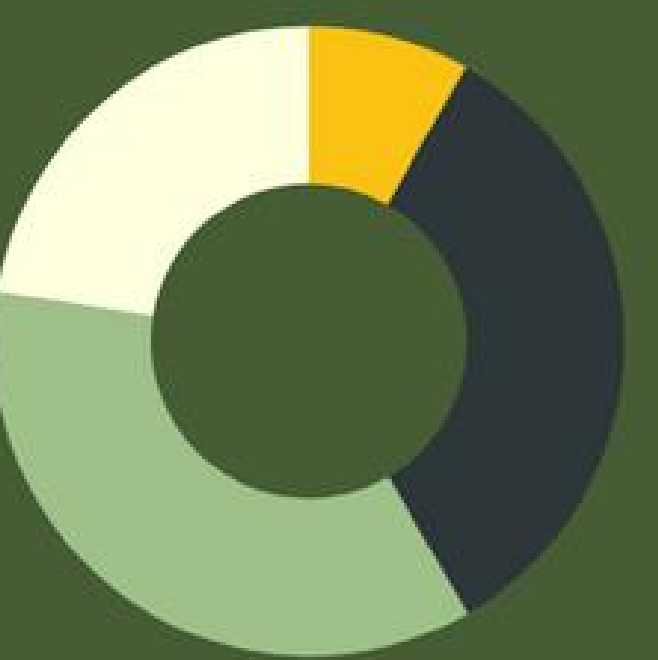
- 18-24 years old (9.7%)
- 25-34 years old (28.6%)
- 35-44 years old (46.3%)
- 45-54 years old (15.4%)

In terms of age, out of 350 respondents, 34 (9.7%) were between 18-24 years old, 100 (28.6%) fell in the 25-34 years age group, 162 (46.3%) were in the 35-44 years range, and 54 (15.4%) were aged 45-54 years.



- full-time employed (61.9%)
- part-time employed (15.8%)
- not employed (22.3%)

Regarding employment status, among 349 participants, 216 (61.9%) were employed full-time, 55 (15.8%) were employed part-time, and 78 (22.3%) were not employed.

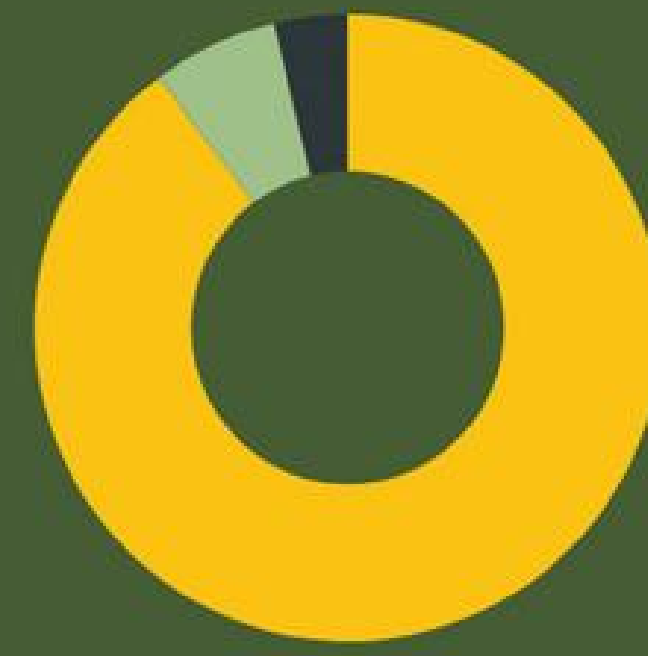


- high school (8.3%)
- completed college (33.3%)
- bachelor's degree (35.9%)
- graduate degree (22.5%)

In the realm of highest level of education completed, out of 351 respondents, 29 (8.3%) had high school education, 117 (33.3%) completed college, 126 (35.9%) held a bachelor's degree, and 79 (22.5%) had a graduate degree.

SURVEY FINDINGS

Concerning sexual orientation, among 340 participants, 305 (89.7%) identified as heterosexual/straight, 22 (6.5%) as gay or lesbian/homosexual, and 13 (3.8%) as bisexual.



- heterosexual / straight (89.7%)
- gay / lesbian / homosexual (6.5%)
- bisexual (3.8%)

Regarding gender identity, out of 349 respondents, 161 (46.1%) identified as men, 182 (52.1%) as women, and 6 (1.7%) as trans/nonbinary individuals.



- men (46.15%)
- women (52.15%)
- trans / nonbinary (1.7%)

In terms of immigration status, among 348 participants, 89 (25.6%) were Canadian citizens, 127 (36.5%) were permanent residents, 107 (30.7%) were temporary residents, and 25 (7.2%) identified as refugee or humanitarian type immigrants.



- Canadian citizens (25.6%)
- permanent residents (36.5%)
- temporary residents (30.7%)
- refugee or immigrants (7.2%)

Finally, when asked about household income before taxes last year, out of 325 respondents, 69 (21.2%) reported less than 15k, 87 (26.8%) fell in the 15k to less than 40k range, 98 (30.2%) had incomes between 40k to less than 70k, and 71 (21.8%) reported incomes of 70k or higher.



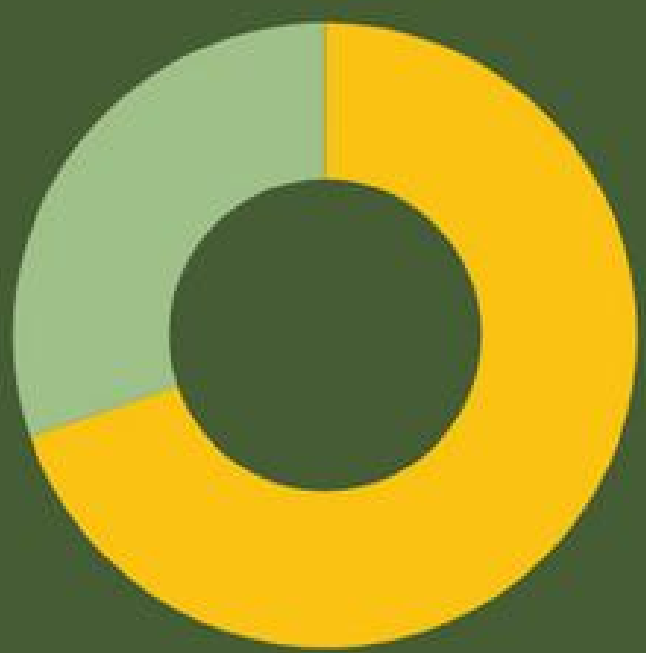
- less than \$15k (21.2%)
- \$15-\$40k (26.8%)
- \$40k-\$70K (30.2%)
- \$70k or higher (21.8%)



SURVEY FINDINGS

HIV TESTING

The findings on HIV testing reveal a proactive approach among the majority of respondents, with a substantial number having undergone testing. The data also highlights the varied locations for testing within Manitoba, indicating a wide distribution of healthcare access points. Respondents' feedback on their testing experience and their openness about HIV diagnoses reflect on the community's engagement and awareness regarding HIV health and testing services.



■ tested for HIV (69.7%)
■ never tested for HIV (30.3%)

In matters of HIV testing, out of 351 respondents who answered the question if they had ever tested for HIV, 245 (69.7%) indicated that they had been tested, while 106 (30.3%) had never been tested.



■ past 3 months (8.1%)
■ 4-6 months ago (12.3%)
■ 7-12 months ago (21.3%)
■ over a year ago (56.6%)

In response to the question regarding when they were last tested for HIV, out of 234 respondents, 19 (8.1%) reported being tested in the past 3 months, 29 (12.3%) had a test 4-6 months ago, 50 (21.3%) were tested 7-12 months ago, and 133 (56.6%) indicated that their last test was longer than a year ago.

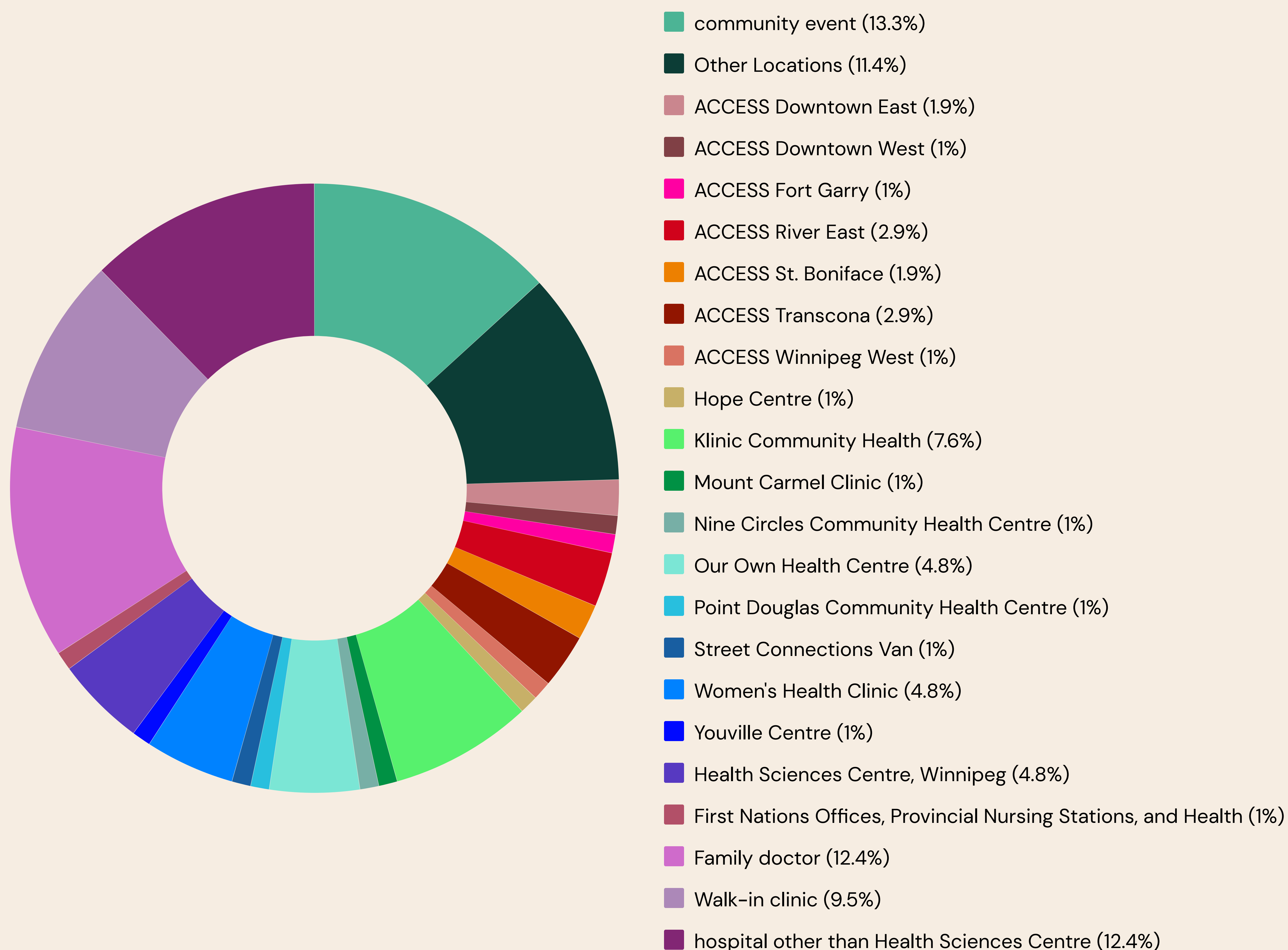


■ yes (51.7%)
■ no (48.3%)

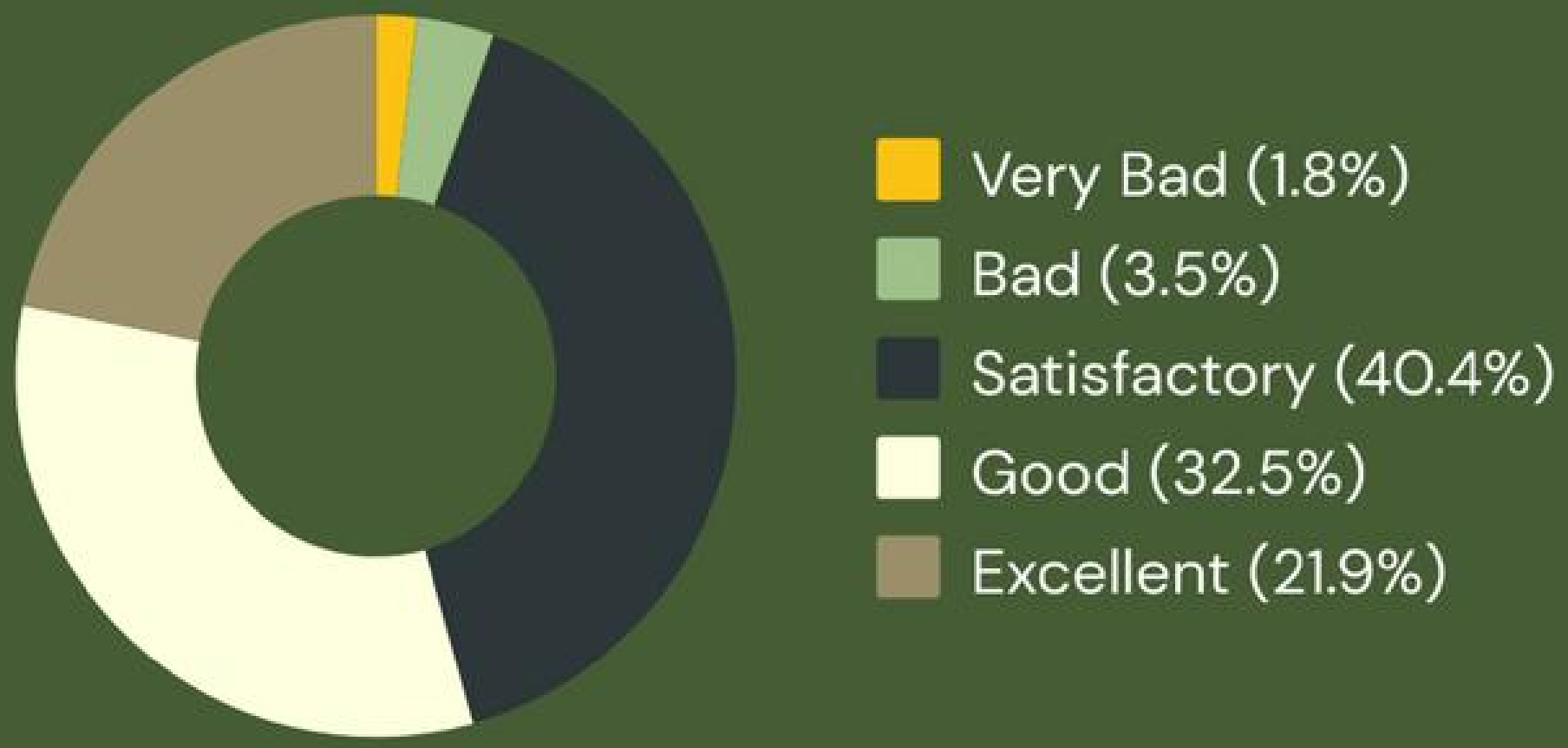
When asked if their last HIV test was conducted in Manitoba, out of 230 respondents, 119 (51.7%) answered "yes" while 111 (48.3%) answered "no."

SURVEY FINDINGS

Among respondents who disclosed the location of their last HIV test in Manitoba, the distribution was as follows: out of 105 respondents, 14 individuals (13.3%) had it at a community event, 12 individuals (11.4%) at Other Locations, 2 individuals (1.9%) at ACCESS Downtown East, 1 individual (1.0%) at ACCESS Downtown West, 1 individual (1.0%) at ACCESS Fort Garry, 3 individuals (2.9%) at ACCESS River East, 2 individuals (1.9%) at ACCESS St. Boniface, 3 individuals (2.9%) at ACCESS Transcona, 1 individual (1.0%) at ACCESS Winnipeg West, 1 individual (1.0%) at the Hope Centre, 8 individuals (7.6%) at Klinik Community Health, 1 individual (1.0%) at Mount Carmel Clinic, 1 individual (1.0%) at Nine Circles Community Health Centre, 5 individuals (4.8%) at Our Own Health Centre, 1 individual (1.0%) at Point Douglas Community Health Centre, 1 individual (1.0%) at the Street Connections Van (Mobile Unit), 5 individuals (4.8%) at the Women's Health Clinic, 1 individual (1.0%) at Youville Centre, 5 individuals (4.8%) at Health Sciences Centre, Winnipeg, 1 individual (1.0%) at First Nations Offices, Provincial Nursing Stations, and Health, 13 individuals (12.4%) at their family doctor, 10 individuals (9.5%) at a walk-in clinic, and 13 individuals (12.4%) at a hospital other than Health Sciences Centre.

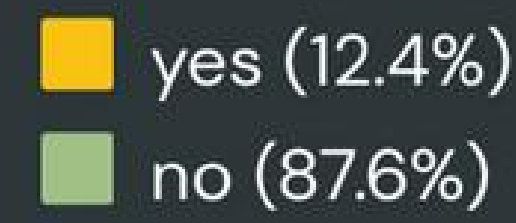


SURVEY FINDINGS

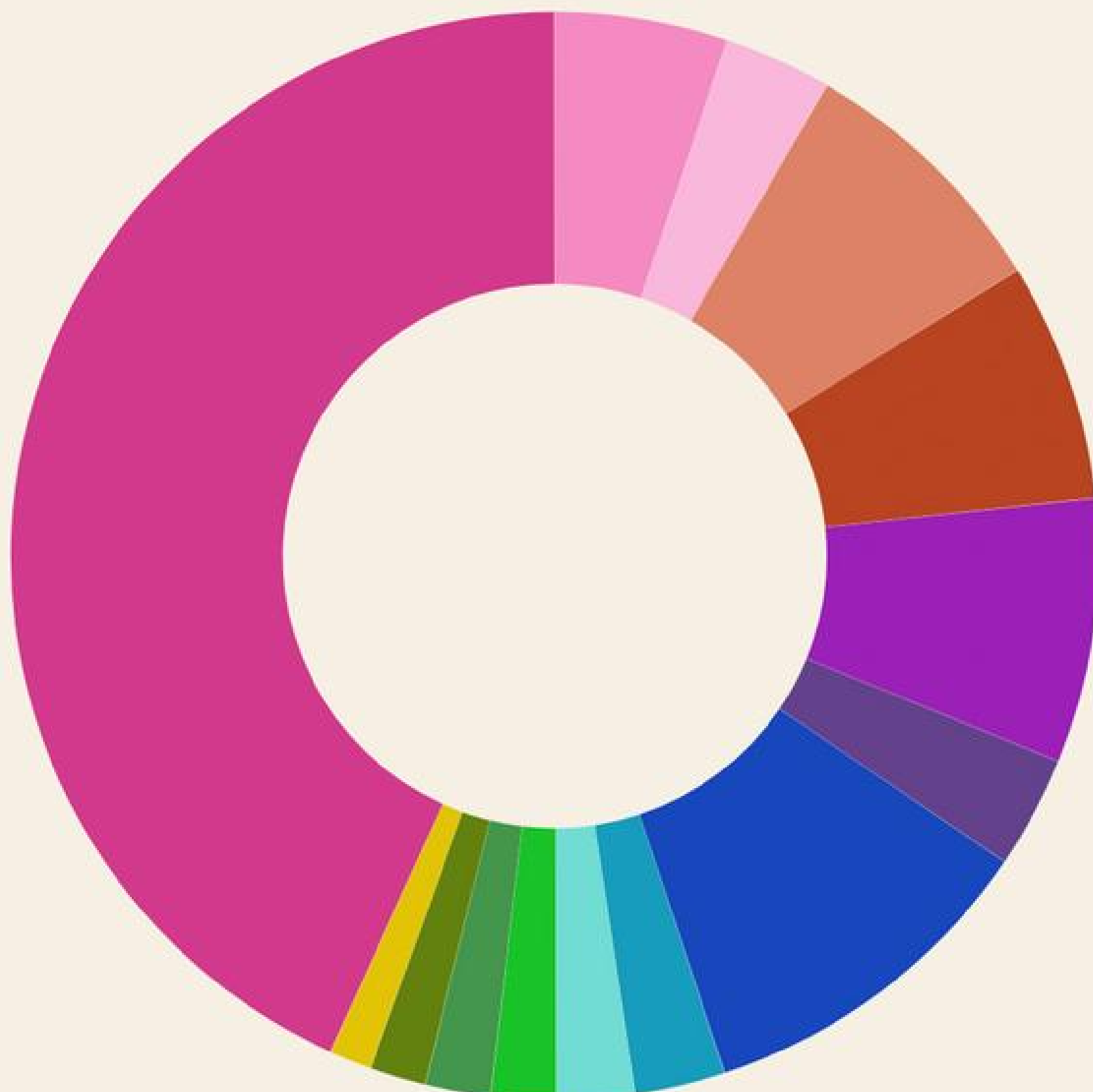


Among respondents who provided feedback on their testing experience in Manitoba, out of 114 respondents, it was found that 2 individuals (1.8%) described their experience as "Very Bad" 4 individuals (3.5%) characterized it as "Bad", 46 individuals (40.4%) found it "Satisfactory", 37 individuals (32.5%) considered it "Good," and 25 individuals (21.9%) reported an "Excellent".

Regarding ever being diagnosed with HIV, out of 233 respondents, 29 (12.4%) answered "yes", while 204 (87.6%) answered "no".



When asked about their history of HIV testing at various locations, 40 respondents (11.4%) had been tested at a private doctor's office, 25 (7.1%) at an HIV counseling and testing site, 61 (17.4%) at a public health clinic or community health clinic, 55 (15.7%) during pregnancy-related appointments, 61 (17.4%) during immigration-related appointments, 26 (7.4%) at sexual health clinics, 81 (23.1%) at hospitals, 21 (6.0%) in emergency rooms, 18 (5.1%) through street outreach programs or mobile units, 15 (4.3%) in correctional facilities, 15 (4.3%) at event-based testing sites, and 13 (3.7%) through online testing programs like "GetCheckedOnline", while 10 (2.8%) had tested for HIV at home using an HIV self-test, with a total of 336 respondents (95.7%) not having used this option.

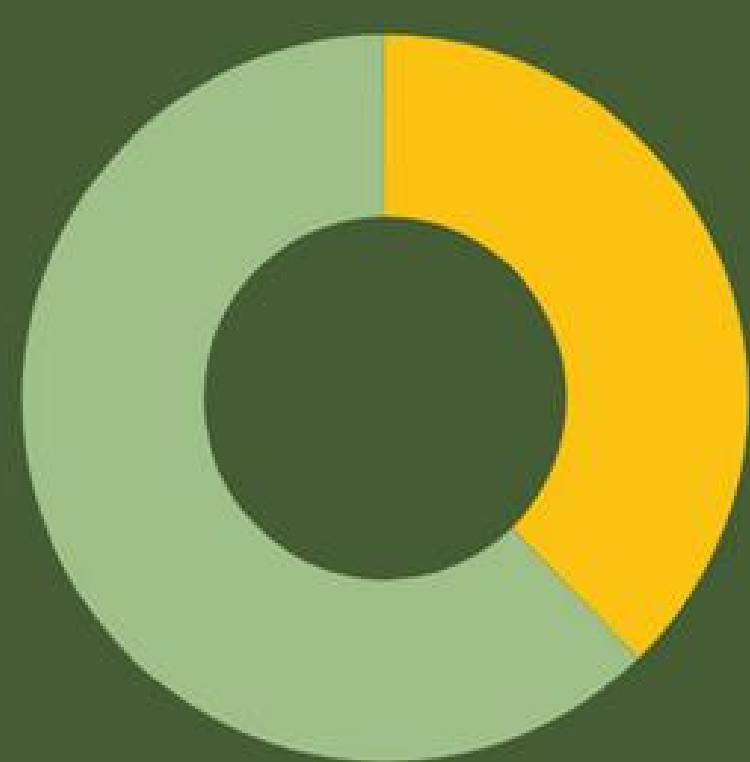




SURVEY FINDINGS

STI TESTING

This section uncovers the prevalence of STI testing among respondents, with a notable portion having been tested for STIs other than HIV. The distribution of testing locations within Manitoba, alongside the reported diagnoses of various STIs, underscores the ongoing need for accessible sexual health services and education within the community.

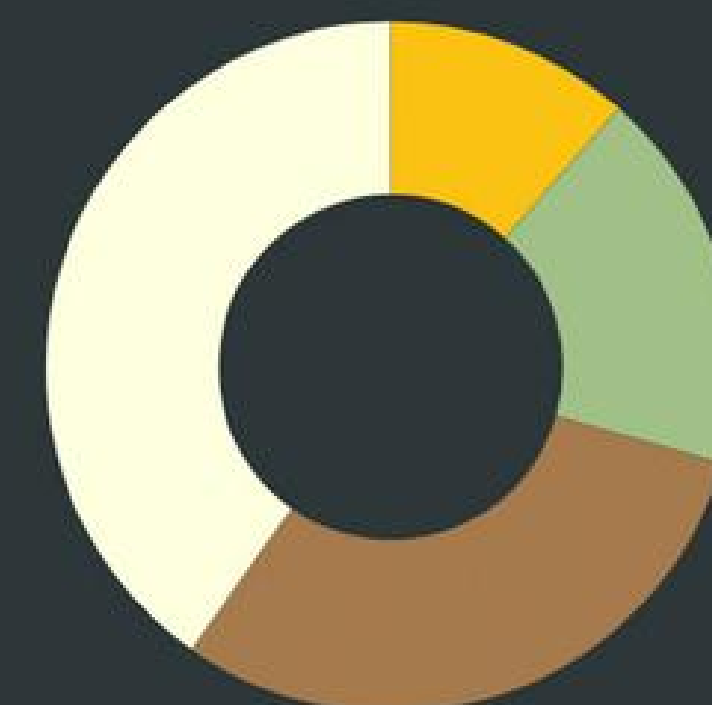


yes (37.7%)
no (62.3%)

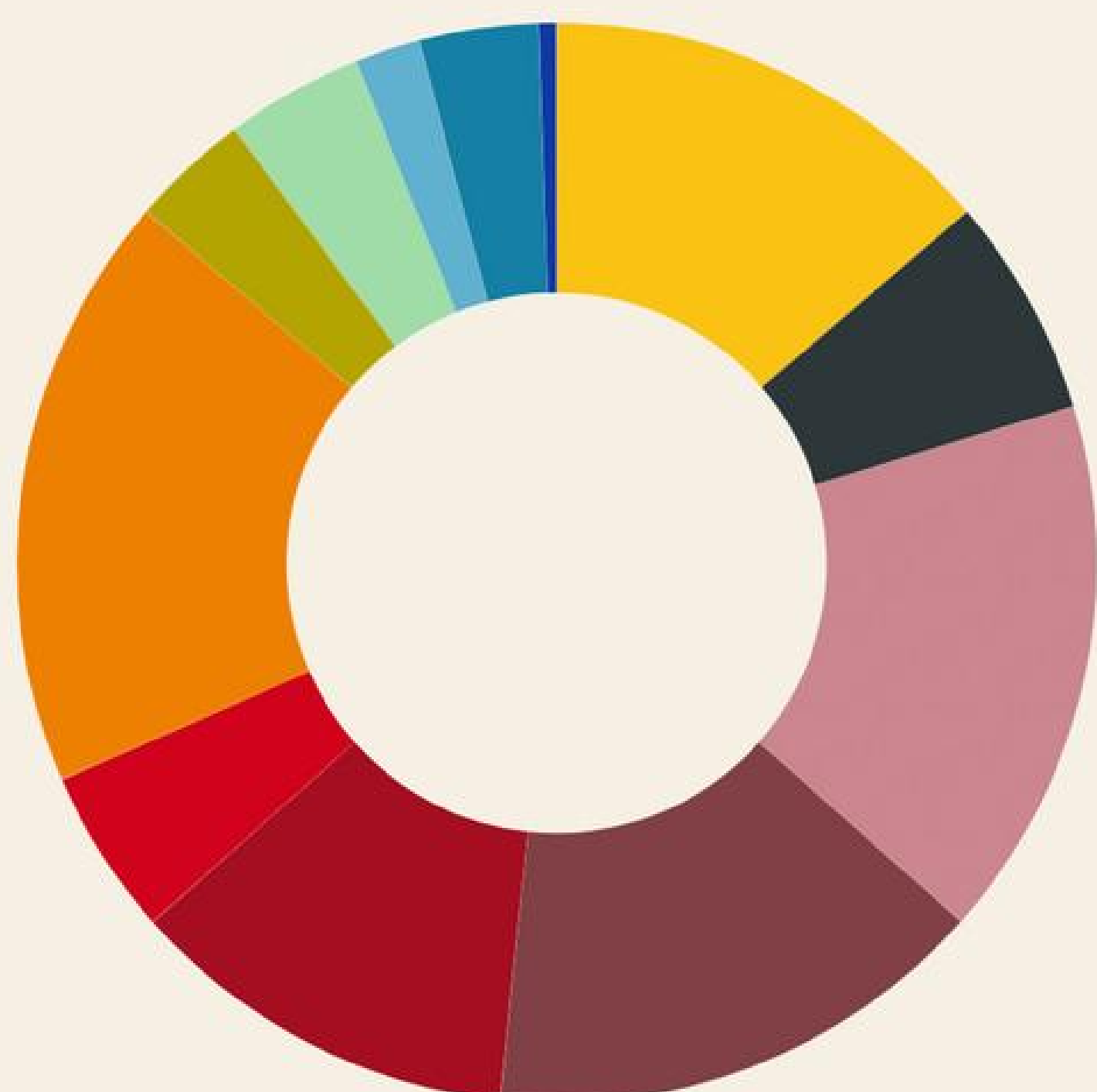
When asked if they had ever been tested for a sexually transmitted infection (STI) other than HIV, out of 329 respondents, 124 respondents (37.7%) answered "yes", while 205 respondents (62.3%) answered "no".

Among those who had been tested, out of 122 respondents, 14 respondents (11.5%) reported being tested in the past 3 months, 22 (18.0%) in the past 4-6 months, 37 (30.3%) in the past 7-12 months, and 49 (40.2%) longer than a year ago.

past 3 months (11.5%)
past 4-6 months (18%)
past 7-12 months (30.3%)
longer than a year ago (40.2%)

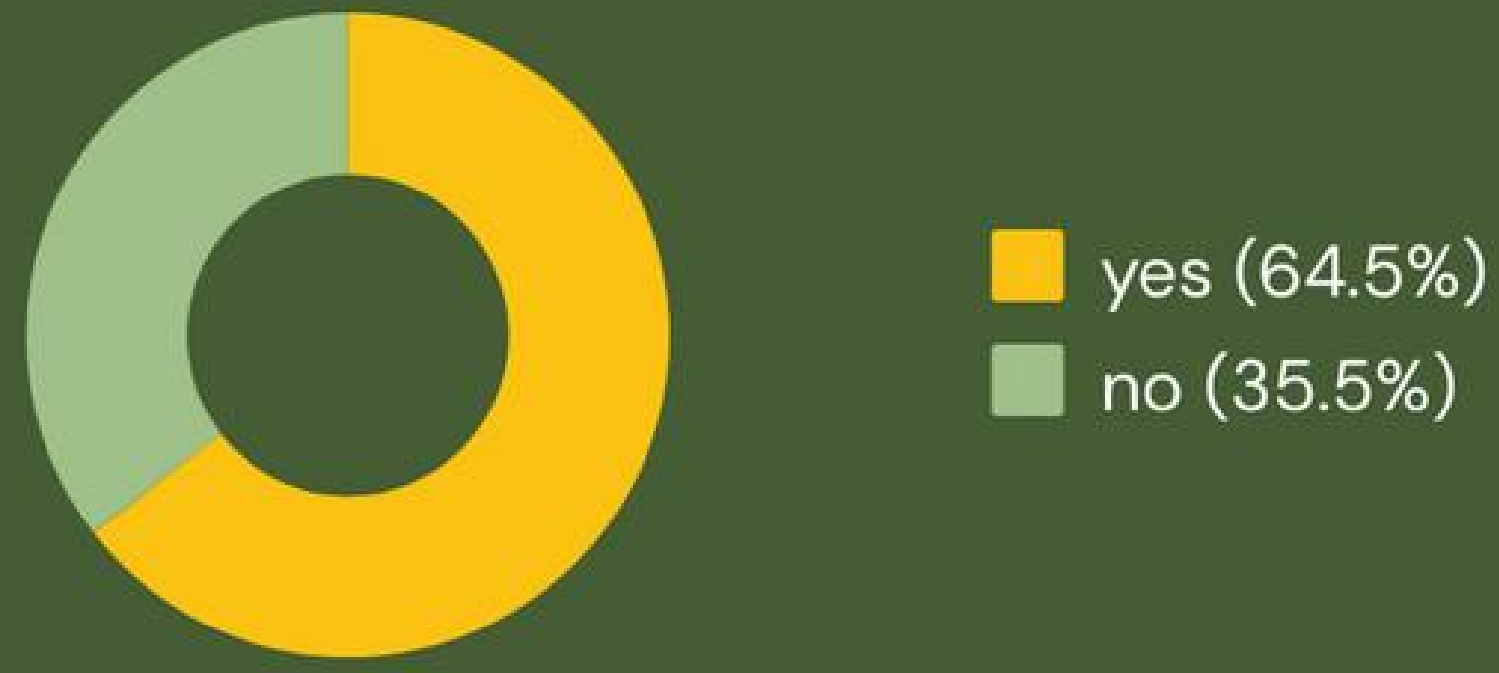


Among respondents who answered the question about where they had ever tested for sexually transmitted infections (STIs), out of 351 respondents, 27 (7.7%) had tested at a private doctor's office, 13 (3.7%) at an HIV counseling and testing site, 32 (9.1%) at a public health clinic or community health clinic, 30 (8.5%) at an appointment related to pregnancy, 23 (6.6%) at an appointment during the immigration process, 10 (2.8%) at a sexual health clinic, 35 (10.0%) at a hospital, 7 (2.0%) at an emergency room, 8 (2.3%) at a street outreach program or mobile unit, 4 (1.1%) at a correctional facility (jail or prison), 7 (2.0%) through event-based testing (e.g., Pride, festival), and 1 (0.3%) through an online testing program (i.e., GetCheckedOnline).



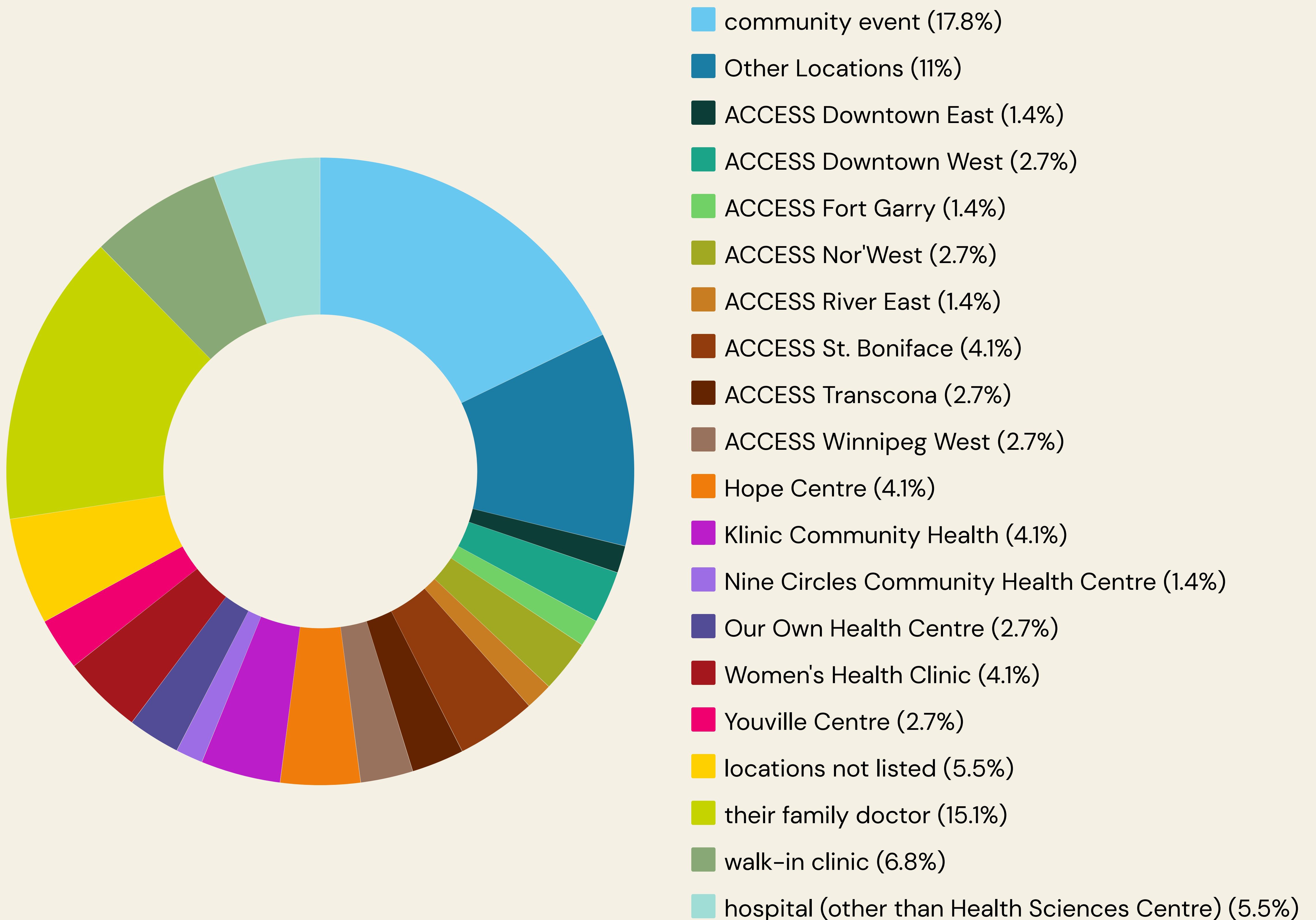
private doctor's office (7.7%)
HIV counseling and testing site (3.7%)
public health clinic (9.1%)
pregnancy-related appointments (8.5%)
immigration-related appointments (6.6%)
sexual health clinics (2.8%)
hospitals (10%)
emergency rooms (2%)
street outreach programs or mobile units (2.3%)
correctional facilities (1.1%)
event-based testing sites (2%)
online testing programs (0.3%)

SURVEY FINDINGS



Among respondents who answered whether their last STI test was done in Manitoba, out of 121 respondents, 78 (64.5%) answered "yes" while 43 (35.5%) answered "no"

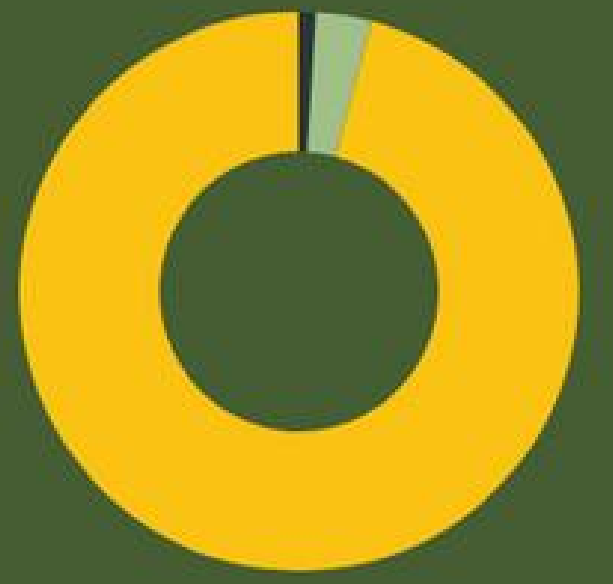
Among those who had their last STI test in Manitoba and answered the location, out of 73 respondents, 13 (17.8%) had it at a community event, 8 (11.0%) at Other Locations, 1 (1.4%) at ACCESS Downtown East, 2 (2.7%) at ACCESS Downtown West, 1 (1.4%) at ACCESS Fort Garry, 2 (2.7%) at ACCESS Nor'West, 1 (1.4%) at ACCESS River East, 3 (4.1%) at ACCESS St. Boniface, 2 (2.7%) at ACCESS Transcona, 2 (2.7%) at ACCESS Winnipeg West, 3 (4.1%) at the Hope Centre, 3 (4.1%) at Klinik Community Health, 1 (1.4%) at Nine Circles Community Health Centre, 2 (2.7%) at Our Own Health Centre, 3 (4.1%) at the Women's Health Clinic, 2 (2.7%) at the Youville Centre, 4 (5.5%) at locations not listed, 11 (15.1%) at their family doctor, 5 (6.8%) at a walk-in clinic, and 4 (5.5%) at a hospital (other than Health Sciences Centre).



SURVEY FINDINGS

Regarding hepatitis C status, out of 313 respondents, 3 respondents (1.0%) currently have hepatitis C, while 10 respondents (3.2%) have had hepatitis C before but cleared the virus. The majority, 300 respondents (95.8%), have never been diagnosed with hepatitis C.

- currently have hepatitis C (1%)
- have had hepatitis C (3.2%)
- have never had hepatitis C (95.8%)



In the past 12 months, out of 351 respondents, 7 respondents (2.0%) were diagnosed with or treated for syphilis, 9 respondents (2.6%) had chlamydia, 12 respondents (3.4%) had gonorrhea, 10 respondents (2.8%) had genital or anal warts, 9 respondents (2.6%) had genital or anal herpes, 13 respondents (3.7%) had non-specific urethritis, 10 respondents (2.8%) had lymphogranuloma venereum (LGV), 10 respondents (2.8%) had bacterial vaginosis, and 4 respondents (1.1%) had trichomoniasis in the past 12 months.



- diagnosed or treated with syphilis (2%)
- had chlamydia (2.6%)
- had gonorrhea (3.4%)
- genital or anal warts (2.8%)
- genital or anal herpes (2.6%)
- non-specific urethritis (3.7%)
- lymphogranuloma venereum (2.8%)
- bacterial vaginosis (2.8%)
- trichomoniasis (1.1%)





HIV Self-Testing and Dried-Blood Spot Testing

UBUNTU-PAMOJA STUDY

SURVEY FINDINGS: SELF-TESTING AND DRIED BLOOD SPOT TESTING

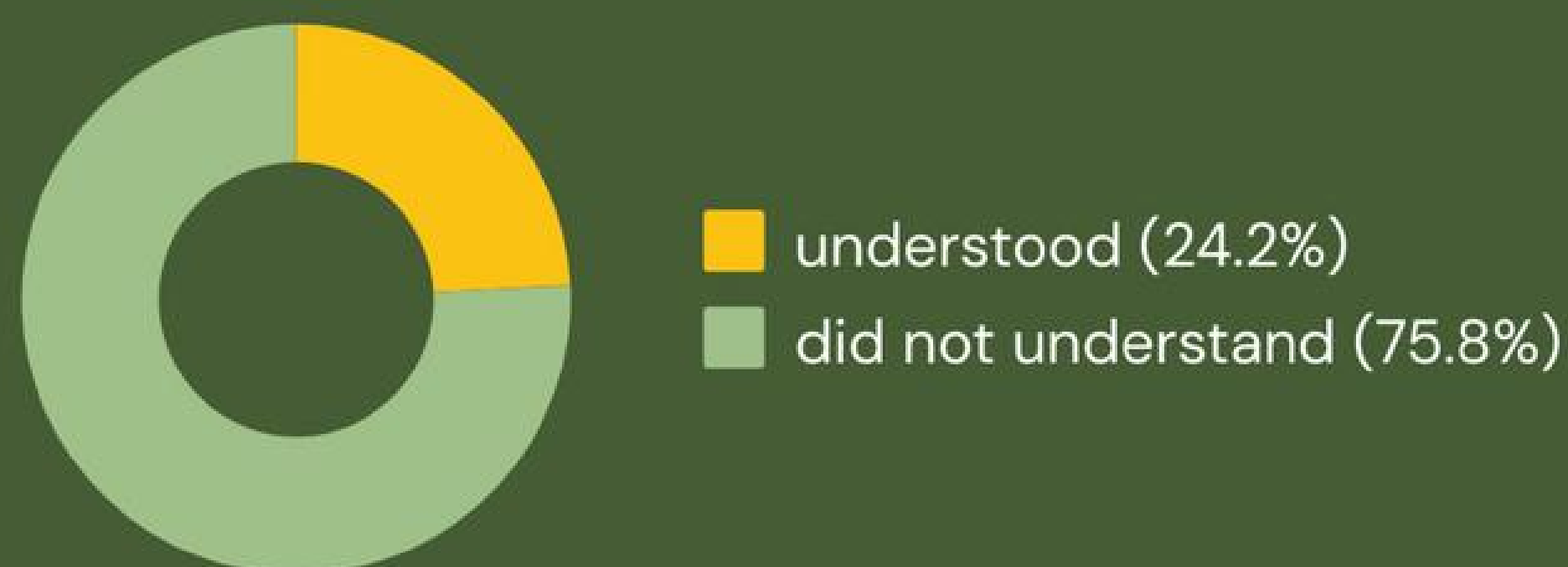
We conducted a provincial online survey with 351 African and Caribbean community members to learn about preferences for different testing methods. When participating in our online survey, participants had the option to request a take-home HIV self-testing kit, or if desired, request HIV or STBBI testing by a trained healthcare provider.



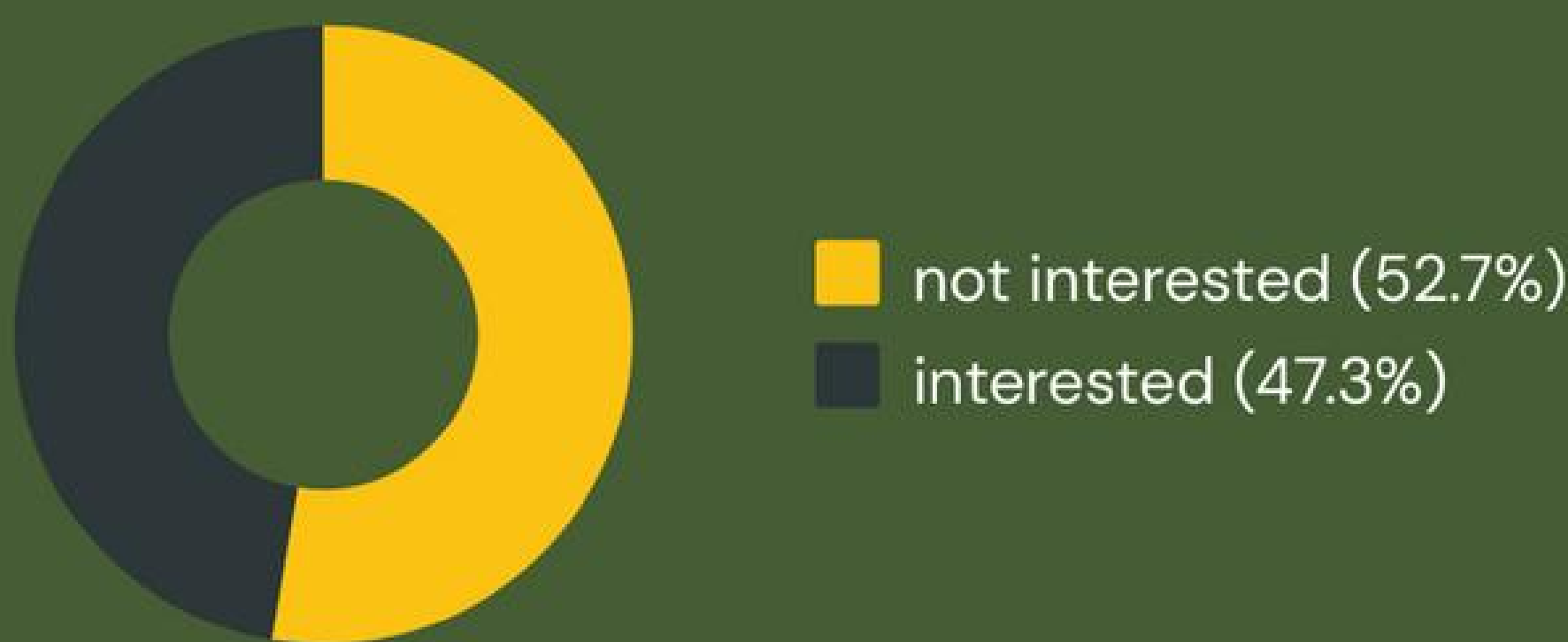
This infographic provides a unique perspective on the health, testing practices, and needs of the community, offering valuable insights for future public health initiatives and policies aimed at enhancing well-being and healthcare accessibility for African and Caribbean communities in Manitoba.

DRIED BLOOD SPOT TESTING

Insights into the awareness and interest levels regarding Dried Blood Spot (DBS) testing among respondents highlight both an opportunity and a challenge in promoting this testing method. While a significant number of participants were unfamiliar with DBS testing, there exists a curiosity and willingness to learn more, suggesting potential for increased adoption with proper education and outreach.



Among the respondents, out of 343 individuals, 83 individuals (24.2%) indicated that they have an understanding of DBS (Dried Blood Spot) testing, while 260 individuals (75.8%) reported not having an understanding of DBS testing.



Regarding interest in doing a DBS test, out of 243 respondents, 128 respondents (52.7%) stated that they have no interest in accessing this type of test for HIV or other STIs, while 115 respondents (47.3%) expressed interest in using it.



When asked if they feel they have enough information to make an informed choice about taking the DBS test, out of 338 respondents, 151 respondents (44.7%) answered "Yes", 117 respondents (34.6%) answered "No" and 70 respondents (20.7%) were unsure.

SURVEY FINDINGS: SELF-TESTING AND DRIED BLOOD SPOT TESTING



- wanting to know about the safety of the DBS test (33.3%)
- seeking information on how to access testing (25.9%)
- wanting to understand the support available (21.9%)
- desiring guidance on self-sampling (25.1%)
- interest in issues related to DBS test (20.8%)

Respondents in Manitoba expressed interest in specific aspects of a DBS testing event or resource, with out of 351 individuals, 117 individuals (33.3%) wanting to know about the safety of the DBS test, 91 individuals (25.9%) seeking information on how to access it, 77 individuals (21.9%) wanting to understand the support available, 88 individuals (25.1%) desiring guidance on self-sampling, and 73 individuals (20.8%) expressing interest in issues related to the DBS test.

HIV SELF-TESTING

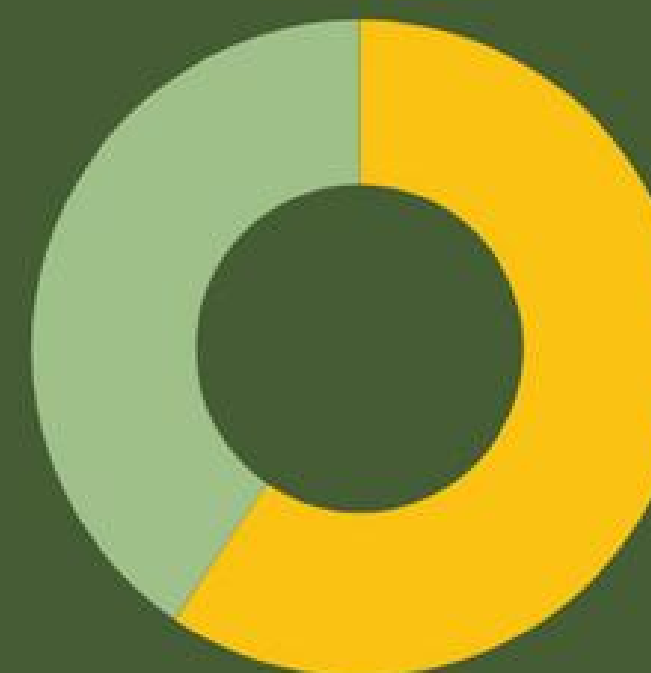
The data on HIV self-testing demonstrates a strong foundational understanding of what HIV self-tests are among the majority of respondents. Interest in utilizing HIV self-testing indicates a move towards more private, convenient testing options. However, the need for more information and assurance on the safety and efficacy of self-testing methods is evident, pointing towards an area for targeted educational efforts.

Out of the 341 respondents, 242 individuals (68.9%) indicated that they understood what an HIV self-test is, while 99 individuals (28.2%) reported not understanding it.



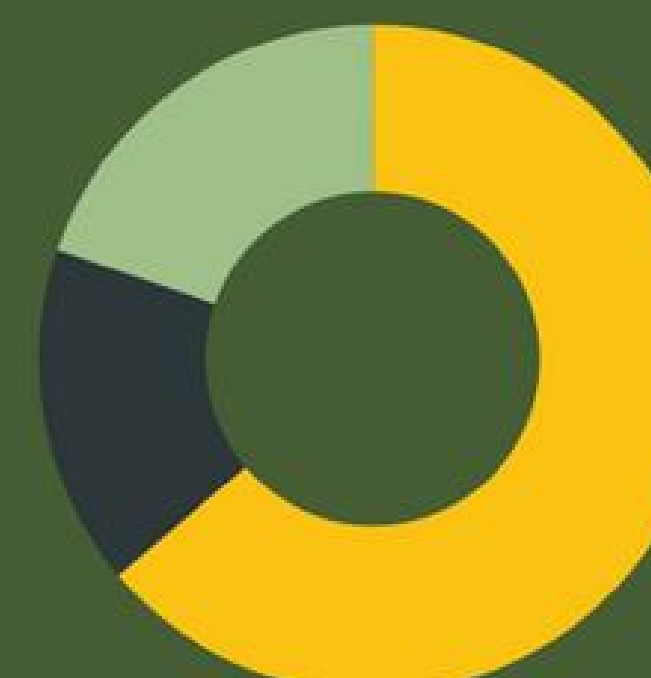
- understood (68.9%)
- did not understand (28.2%)

Among the 276 respondents in Manitoba, 165 individuals (59.2%) expressed interest in using an HIV self-test, while 111 individuals (40.2%) indicated no interest in accessing this type of test for HIV.



- interested (59.2%)
- not interested (40.2%)

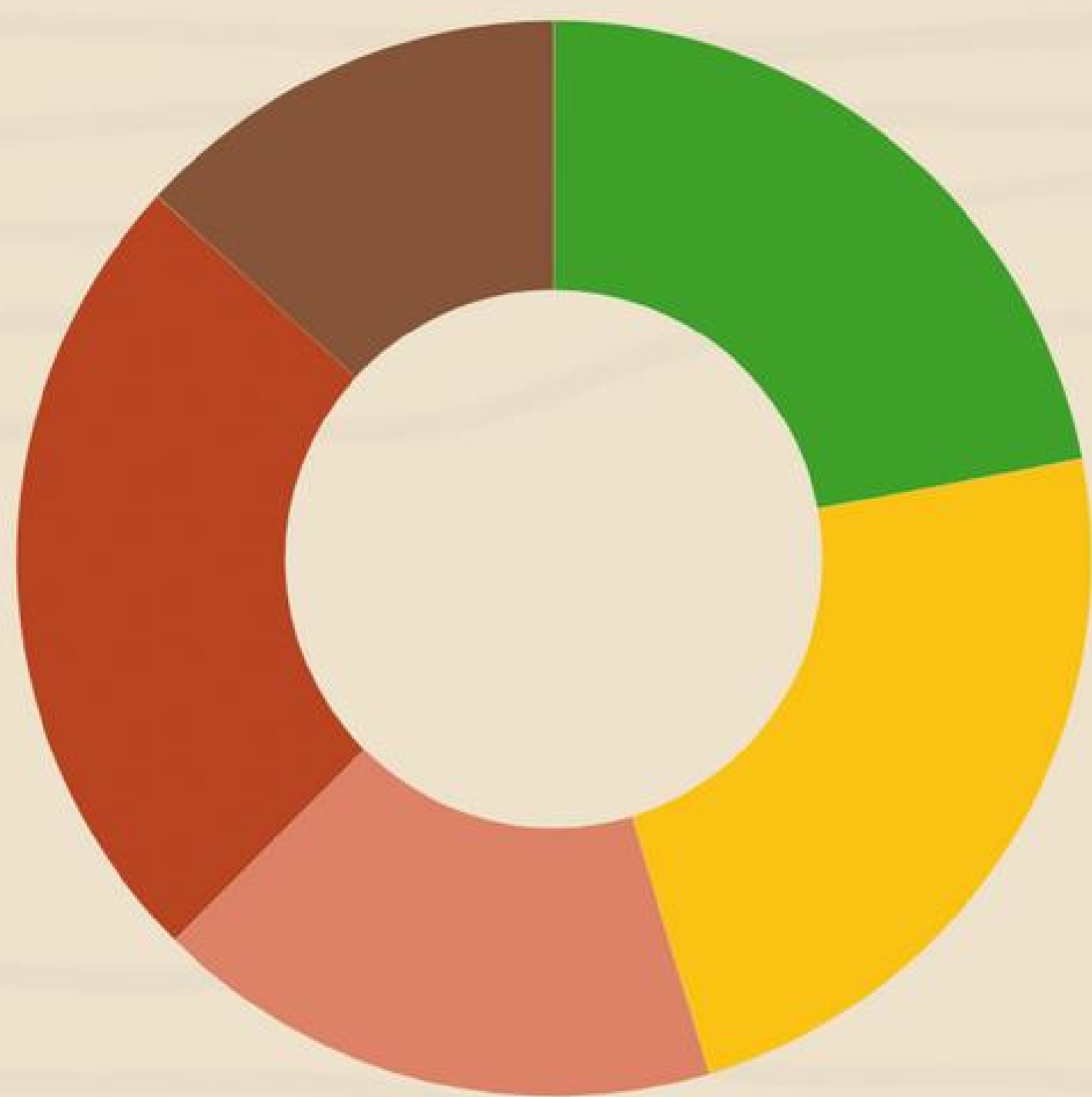
Regarding having enough information to make an informed choice about taking the HIV self-test, out of 351 respondents, 224 individuals (63.8%) felt adequately informed, 58 individuals (16.5%) believed they lacked sufficient information to make such a decision, and 69 respondents (19.7%) did not provide a response.



- felt informed (63.8%)
- felt uninformed (16.5%)
- no response (19.7%)

SURVEY FINDINGS: SELF-TESTING AND DRIED BLOOD SPOT TESTING

When asked about their preferences for information regarding an HIV self-testing event or resource in Manitoba, out of 304 respondents, 67 individuals (22%) expressed an interest in evidence on the safety of HIV self-sampling, 71 individuals (23.3%) wanted to know how to access HIV self-tests, 52 individuals (17.1%) were interested in support for people taking HIV self-tests, 74 individuals (24.3%) wanted information on how to perform HIV self-tests, and 40 individuals (13.2%) were concerned about issues with HIV self-tests



- expressed an interest in evidence of HIV self sampling (22%)
- wanted to know how to access HIV self-tests (23.3%)
- interested in support for people taking HIV self-tests (17.1%)
- wanted information on how to perform HIV self-tests (24.3%)
- concerned about issues with HIV self-tests (13.2%)

Out of the 164 respondents, 49 individuals (29.9%) expressed interest in receiving an HIV self-testing kit at their home residence, while 115 individuals (70.1%) declined.



- interested (29.9%)
- declined (70.1%)



The Ubuntu-Pamoja study is a collaboration between community members, service provider agencies, and University of Manitoba. For more information on this study, please visit:

villagelab.ca/ubuntu-pamoja

or email:

villagelab@umanitoba.ca

Relationship Between Demographics and HIV Testing

Below we present bivariate analyses indicating demographics associated with ever being tested for HIV among Black, African, and Caribbean community members in Manitoba. When examining the HIV testing history in different age groups, among a total of 342 respondents, 30 individuals (8.8%) were between 18-24 years old, 97 individuals (28.4%) aged 25-34 years, 161 individuals (47.1%) in the 35-44 years age group, and 54 individuals (15.8%) aged 45-54 years reported having been tested for HIV. On the other hand, among those who have not been tested, 18 individuals (17.3%) were in the 18-24 years age group, 29 individuals (27.9%) in the 25-34 years age group, 44 individuals (42.3%) in the 35-44 years age group, and 13 individuals (12.5%) in the 45-54 years age group.

When considering respondents' HIV testing history in relation to their current employment status, we find that out of the 238 individuals who have been tested for HIV, 160 (67.2%) are employed full-time, 29 (12.2%) are employed part-time, and 49 (20.6%) are not currently employed. On the other hand, among the 103 individuals who have not been tested for HIV, 52 (50.5%) are employed full-time, 24 (23.3%) are employed part-time, and 27 (26.2%) are not currently employed.

When analyzing the HIV testing with respect to the respondents' education levels, we observe that out of the 239 individuals who have been tested for HIV, 17 (7.1%) have a high school education, 69 (28.9%) have completed college, 87 (36.4%) hold a bachelor's degree, and 66 (27.6%) have a graduate degree. On the other hand, among the 104 individuals who have not been tested for HIV, 11 (10.6%) have a high school education, 44 (42.3%) have completed college, 38 (36.5%) hold a bachelor's degree, and 11 (10.6%) have a graduate degree.

When examining testing based on the respondents' sexual orientation, we find that out of the 237 individuals who have been tested for HIV, 207 (87.3%) identify as heterosexual/straight, 21 (8.9%) as gay or lesbian/homosexual, and 9 (3.8%) as bisexual. On the other hand, among the 95 individuals who have not been tested for HIV, 92 (96.8%) identify as heterosexual/straight, 0 (0.0%) as gay or lesbian/homosexual, and 3 (3.2%) as bisexual. When analyzing HIV testing based on respondents' gender identity, we find that out of the 233 individuals who have been tested for HIV, 113 (48.5%) identify as men, and 120 (51.5%) identify as women. Conversely, among the 103 individuals who had not been tested for HIV, 45 (43.7%) were men, and 58 (56.3%) were women.

When examining HIV testing based on respondents' immigration status, we find that out of the 238 individuals who have been tested for HIV, 67 (28.2%) are Canadian citizens, 98 (41.2%) are permanent residents, 55 (23.1%) are temporary residents, and 18 (7.6%) are refugee or humanitarian type immigrants. On the other hand, among the 102 individuals who have not been tested for HIV, 20 (19.6%) are Canadian citizens, 25 (24.5%) are permanent residents, 50 (49.0%) are temporary residents, and 7 (6.9%) are refugee or humanitarian type immigrants. Looking at the percentage within each income category, 59.7% of those with incomes less than, \$15,000, 82.7% of those with incomes between \$15,000 to less than \$40,000 65.3% of those with incomes between \$40,000 to less than \$80,000, and 71.8% of those with incomes of \$80,000 and above have been tested for HIV. On the other hand, among those who have not been tested for HIV, 27 individuals (28.4%) had incomes less than \$15,000, 14 individuals (14.7%) fell in the income range of \$15,000 to less than \$40,000, 34 individuals (35.8%) had incomes between \$40,000 to less than \$80,000, and 20 individuals (21.1%) had incomes of \$80,000 or more.

Summary of Post-Test Interview Findings

We conducted a post-test interview with 10 African, Caribbean and Black Community members after the online survey to understand their experiences of testing for HIV by using the self-test kit, going to the clinic for dried blood spot test or point of care test. Most of the participants interviewed opted for the self-test because of its convenience and clear instructions. Other participants opted for the dried blood spot test because of its ability to test for other STBBIs and not only HIV. The findings from the interviews provide a unique viewpoint on the different HIV testing practices adopted by members of ACB community which provides valuable information on their decision and motivation for testing as well as the importance and barriers for HIV testing. The findings from the interviews will inform future public health initiatives and policies aimed at improving the well-being and healthcare accessibility for the African and Caribbean communities in Manitoba.

Theme 1: First Time Testing for HIV

Participants recounted their initial HIV testing experiences, which included testing due to surgery, pregnancy, employment, and routine health screenings. *“The first time when I did a blood check for a minor surgery. So, I’ll say like 10 times. Before it was for a minor surgery. It’s probably blood work you do before surgery. Then the next two times were employment screening and then after that pregnancy screening. I was pregnant twice. I worked in that place for four years. We used to do that every year. And then I also had another major surgery, myomectomy, and did blood screening. It was like 12 to 14 times”* (Participant # 04).

Theme 2: Decision and Motivation for Testing

Participants expressed their decision and rationale for selecting a self-test, dried blood spot test, and/or point-of-care test. *“It was really because of transportation. I have a little one that I’m still looking for daycare for her, so I just felt like because of transportation I’ll go for the self-administered test, so it was mailed to me at home. I’m a bit familiar with running tests because I interned in a hospital at the university, so it was not something new. So that was why I opted to self-administered test”* (Participant # 07).

Similarly, another participant described that *“I decided to use the self-test because of how handy it is, it is something I can just do and move on with every other daily routine. So, I decided to have that self-check test, the one I can just do at my convenience and have other things to do. Yeah, just like someone who is going to a clinic for your blood work, right, you know you must wait until you get there. Sometimes you can wait for 10, 15, and 20 minutes depending on how busy the place is at that moment. I did not want to stumble into that tight schedule. I prefer it at my own convenience, right?”* (Participant #10).



One of the participants who was motivated based on how the options for testing were presented recounted that *“I think it was the way the options were presented. So, the point of care one seemed like it was going to do more. And since I’m not scared of needles, I really wanted to check all the parameters, so I just went with that one. And, of course, I knew I would have time to drive to Winnipeg to do the ... Well, if all the tests were the same, were going to test the same parameters, I would have done the one that you ship to me. Because of time constraints and distance”*. (Participant #03)

Likewise, one more participant revealed that *“I thought that it was a long time since I took the test and when I was reading the questionnaire, I came across all sorts of sexually transmitted diseases, some that would even be in your body that you would not know about or something. I was just thinking I can’t remember, I cared less about them but at least for this age you must be committed to your health. One of the questions was saying you can have it and you won’t know or something like that, it would be silent in your body. So, I said, well just let me do it and the one they said they would send the kit home, I don’t know if I must pinch myself, I was thinking no I don’t think I’ll have the strength to do that, let me just go somewhere. I prefer somebody to pinch me with the needle rather than doing it myself, so that’s why I said let me just go. And I was thinking I won’t be able to get it right, let me go to the professionals. And I think this dried blood will do a lot of other investigations, right, other than the one that was sent to you at home, the kit. So, I was thinking this one would be extensively done, so that’s why I opted for the dried blood one”* (Participant #02).

Additionally, one of the participants shared that they decided to get tested because they had not taken an HIV test in a long time. *“I was motivated to do the test because it’s been long since I did it and I know that people are encouraged, like, occasionally, to know your status. Despite the fact, like, maybe you say you are faithful to your partner, your partner is faithful to you, there are other modes of contracting HIV, not about maybe sexual intercourse, there could be other modes of contracting it. So, it’s good to know your status. It’s been years since I did it, so if I were to be asked my status, maybe I would have been giving someone my status maybe years back. So, because it’s been long, I did it. That was the main motivation that prompted me to go for that self-test kit”* (Participant #01)

Another participant recounted that *“Sometimes a family member of yours could also need a blood transfusion. Overtime in Africa, I have been involved in donating blood. So, if I’m not sure, even though they would take this blood to the lab, you must be sure of what you are giving out in the first place. For me to say, okay, why not check my blood if I have HIV. You should be*

able to know your status. So, I'm doing that also in preparation to help in the community should there be a need for a blood transfusion. My family needs it. We know our genotypes, right? I know my genotype. If I find a need, I know it. So, for me to donate, I would say, this is my genotype. And the last time I checked my HIV status, I was negative. So, with this, I am also getting myself ready should there be a need to support the community with my blood". (Participant #10)

Theme 3: Post-testing Experiences

Participants described their experiences of self-test, dried-blood spot test and point of care test. "It was a lot more stressful for me first because I had to go there. Another thing is I think the location of the place, maybe it was me, but it was not really very clear, and where I parked, it looked like a parking area. Locating the place, because I was expecting to see a big billboard, a big notification, or an address of the place, to know where I was going then, but it was not there, and I had to go all around to the entrance of the building. I did see that so okay, this is the place, but then they said you must turn back around because there is construction going on or something, so I had to tour all over again. So, locating the place was not very easy for me so I'll start with that. Secondly, the whole process is not like the self-test where you see just a drop of blood will be enough. The fact that I had to squeeze my fingers, I had to stroke my hand, it was a bit more difficult for me, so I had to do that. I was there for more than 20 to 30 minutes because the blood wasn't coming out. I think we only got four so the first, second, third, and then the fourth was very faint. But then the person that was doing the test said, okay, this blood will cover it so we can make do with what we have. So, it was a difficult process for me, and I think if I had to do this again, I would not do the DBS" (Participant #04).

Some of the participants described their experiences of HIV testing as the following: "The instructions were very clear. I went to my basement, I have a bathroom in the basement, and, you know, I turned the light on, washed my hands, and proceeded to do it myself. It was a bit, like, I was a bit anxious at first, you know. Even though, you know, I'm an adult and I'm a grown man, it's still sort of, you know, something that you don't do all the time, so it was a little, like, there was some anxiety. But I also think, in the long run, it's better to be in the know than be scared" (Participant #05).

Other participants also described their post-testing experiences as follows: "The only thing that I had challenges with was going through the instructions, because I didn't quite understand the instructions as it were. If I had done that, I wouldn't have pierced myself twice. I got myself pierced twice because I was unable to grasp the instructions. But on the second point, I got the instructions clearly figured out. I followed it. It worked out. So, I would suggest clearer instructions are given out.

Sometimes there are instructions that you must go over and over to understand, right? You are not the medical personnel. I don't know how it works, right? So, I needed detailed information. When we went to do it over again, we were able to understand just how it works and we followed" (Participant #10).

"It wasn't bad, as well. Given that I know how waiting times are, what they are like in Canada these days, mine wasn't that long. There was an initial misunderstanding about whether I'm scheduled to do the test or not, but that got sorted out in less than two minutes. And then I was asked to wait somewhere. I waited just a little while, not more than five to seven minutes, and then I got called in. The testing was explained to me and then I went into the (inaudible), where they drew the blood sample. So, it wasn't... I didn't get frustrated; I didn't get flustered. It wasn't bad at all" (Participant #03).⁴¹ "I liked the professionalism of the nurse that attended to me. I liked the communication process, and I liked the fact that I didn't have to be scheduled after and while doing the testing the lady communicated and explained each step to me, which I liked, and it made me to be comfortable. The nurses were time conscious, I was scheduled at 9:00 and I think we started around 9:15, thereabouts, so I didn't have to wait too long before I was attended to. That's one aspect of professionalism, keeping to time. And like I said earlier, clear communication, she explained each process before we started and along the way. That's part of the professionalism I was talking about" (Participant #08).

Theme 4: Test Notifications

Participants were asked how they were notified after going for the dried blood spot test. *"I haven't received any notification from the clinic, but I was told that if I didn't get any call from them for the result, I should call and could reach them in a second. I didn't call because I felt okay, if there was something wrong, they would have reached out. And the fact that I have done the self-test again, I felt okay, all is good, but they told me they're supposed to call me, but they didn't call me. They said if I didn't receive any call, they gave me a number to call, but I didn't see their call, and I didn't call also because I just felt okay, maybe my results are okay" (Participant #04)*

In addition to test notification one participant explained that *"Honestly, I did not even think about the test results until I saw the email. I wasn't because maybe I'm pretty sure about myself, I'm not promiscuous and I trust my husband too. And I didn't see any of the symptoms they said would be happening to you. Yeah, there used to be a lot of blood tests, but not related to sexually transmitted, I think there is anything wrong with me. The only testing I do is maybe I have back pain or if I'm coughing or they just want to check my blood to discover something, maybe because of my high blood pressure or things, that's all. I'm not worried about the test results, honestly. If it's something that has to do with maybe my kidney now or maybe I'm having a pain inside my lungs and they want to test for cancer, yeah maybe I would. But this one, I'm not bothered" (Participant #02).*

One more participant recalled that *“Like I said, I was given a paper with a phone number on it, and I was told to call the number after four weeks, which the four weeks would have been around January 14, but unfortunately before that day I lost the paper, so I wasn’t able to contact the phone number to get the results. So, the process would have been for me to call the number to get the results of the tests. A lot of times they often say that if the clinic doesn’t call you, it means that there’s nothing they want to convey to you”* (Participant #08).

Discussions

Our findings from interviews underlined structural and systemic complexities inherent in HIV testing for African, Caribbean, and Black (ACB) communities in Manitoba, particularly as they relate to ethical considerations. Participants expressed concerns about confidentiality, privacy, informed consent, and how HIV testing could affect immigration status, health insurance premiums, and the involvement of authorities such as the police. The recollection of the ACB communities being subjected to serve as mere ‘guinea pigs’ in various research endeavors was also cited, and this posed a barrier to testing. These concerns expressed by ACB communities regarding the collection and dissemination of HIV/STBBI biomaterial can be seen as a manifestation of structural violence. Therefore, the findings emphasized the need for improved communication and transparency regarding the handling and storing samples and the potential consequences of testing, especially concerning immigration and legal matters.

The findings from the survey also suggested that many participants were accepting of the home HIV self-sampling to know their state of health as a way of empowering themselves and based on the convenience of its use. Some other participants also agreed to visit the clinic to access DBS self-sampling and point-of-care testing. Nevertheless, study findings notably showed that the HIV self-test sampling is a feasible testing option to engage the ACB community to respond to current and pressing knowledge gaps concerning HIV/STBBI testing and linkages to care for African and Caribbean migrant communities in Manitoba.

However, the conversation around what individuals would do if they received a positive result from a self-testing kit revealed deeper insights into the needs and challenges faced by the ACB community in connecting with the healthcare system. Some participants expressed concerns about the next steps following a positive result. Many highlighted the necessity for clear, accessible information and support systems to navigate the subsequent stages of care.

The post-test interviews also exposed ACB people's experiences of testing using a self-test, dried-blood spot, and point-of-care test, including highlighting participants' decisions and motivation for testing, their first-time testing for HIV, and test notification. Participants described their testing experiences as facing stress and having difficulties locating the clinic, extracting blood samples from their fingers during self-testing, while highlighting the lack of clarity in self-testing instructions. Removing these barriers is essential for promoting ACB people's access to services beneficial in reducing the HIV burden and prevalence in the community.

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Implications for Research, Service Provision and Policy

Understanding the unique needs and challenges faced by ACB communities concerning HIV testing is essential for developing targeted and effective interventions that can improve testing rates, linkage to care, and overall health outcomes. By addressing the specific needs and concerns of ACB populations in the context of HIV testing, we can work towards reducing HIV-related disparities and advancing health equity for all individuals affected by HIV or other sexual-related diseases. The Ubuntu-Pamoja study's insights have led to comprehensive recommendations from the survey and interviews for researchers, service providers, and policymakers to enhance HIV/STBBI testing, care, and health initiatives within African and Caribbean communities. These recommendations are elaborated below.

Recommendations

For Researchers

Ethical Practices in the Collection of Biological Samples

Researchers should endeavour to navigate ethical challenges with care, prioritizing individual rights and confidentiality during HIV testing within ACB communities. Policies should promote openness, transparency, and respectful practices concerning the ownership and use of biomaterials.

Sustained Research and Community Engagement

Continuous exploration of the health needs and outcomes of ACB communities is essential to inform health policy and practice improvements. An ongoing dialogue between researchers and the community is crucial to ensure that health initiatives are responsive to community needs and preferences.

Continuous Monitoring and Feedback

Researchers should continuously monitor adoption rates and gather community feedback on HIV self-tests and DBS to assess the impact of educational interventions and support services. This will help refine testing services and improve the design and distribution of testing kits.

For Service Providers and Policy-Makers

Expansion of Testing Options and Accessibility

Service providers should increase the availability of take-home HIV self-testing kits, as they are currently underutilized. Promoting event-based and mobile unit testing strategies can effectively reach community members. Strengthening support for healthcare services at community events and local health centers is also essential to address healthcare access gaps and testing disparities among marginalized ACB communities. Health services should be inclusive and sensitive to the needs of individuals across all sexual orientations and gender identities.

Addressing Concerns Around Biological Samples

To ensure the success of HIV self-testing and other related initiatives, it is crucial to address concerns around biological samples. A key recommendation is to provide comprehensive information to individuals seeking testing about the handling and fate of their samples and results. Clear communication should be established regarding:

- Who receives the test results
- Why results of certain sexually transmitted and blood-borne infections (STBBIs) are reported to public health authorities
- Protocols followed by laboratories in handling the samples

Transparency about the fate of biological samples is essential—whether they are destroyed after testing or not. Ensuring that individuals are fully informed about these processes can build trust in the healthcare system and alleviate concerns about privacy and misuse of personal health information.

Education, Outreach, and Awareness Initiatives

Educational efforts around HIV self-testing, DBS testing and other methods, should be increased, focusing on its safety, efficacy, and benefits to address the significant lack of understanding among the community. Clear and accessible instructions for performing HIV self-tests and DBS tests should be provided. Comprehensive sexual health education programs are needed to raise awareness and reduce the stigma associated with HIV and STBBI. Outreach efforts should inform community members about the importance of regular testing and how to access testing options. Safety concerns should be addressed, and robust support systems, including hotlines and online resources, should be offered.

Culturally Sensitive Services and Education

Service providers should offer culturally sensitive services that acknowledge the diversity within ACB communities and provide services in languages spoken by these communities. Creating safe and welcoming environments is essential for ACB individuals seeking HIV and STBBI services. Educational initiatives should demystify assumptions about HIV, promote community outreach, and strategically raise awareness through various communication channels. Healthcare professionals should engage in open discussions with patients about HIV testing and related services. Adopting an anti-oppressive framework is crucial to address fears related to immigration status and health insurance and promote equitable access to testing services.

For Advocates

Empowerment through Knowledge

Advocates should work to empower ACB communities with knowledge about HIV/ STBBI testing and care. By understanding the benefits of various testing methods and engaging in community-tailored health initiatives, individuals can make informed decisions about their health.

Stigma Reduction

Advocates should support educational and awareness initiatives designed to reduce the stigma associated with HIV and STBBI. Creating an environment where testing is normalized and openly discussed is essential.

Supportive Networks

Advocates should promote robust support systems, including hotlines and community-based support, to provide guidance and address concerns surrounding HIV/STBBI testing. This ensures individuals have access to resources that help navigate their health choices and challenges.

Conclusions

The Ubuntu-Pamoja study provides critical insights into the experiences and perspectives of African, Caribbean and Black communities in Manitoba regarding HIV and STBBI testing.

This comprehensive research highlights the complex interplay of cultural, ethical, and systemic factors that influence testing practices and healthcare access within these communities. The findings reveal significant concerns about confidentiality, privacy, and data misuse, underscoring the mistrust towards institutions such as the police, child welfare, and immigration authorities. These concerns emphasize the need for greater transparency, informed consent, and control over health data to build trust and encourage participation in HIV testing. The study also underscores the feasibility and acceptability of HIV self-testing and clinic-based dried blood spot testing as effective methods to engage ACB communities. However, challenges with self-testing instructions and blood sample collection indicate the need for improved educational materials and support systems. The recommendations derived from this study provide a roadmap for researchers, service providers, policymakers, and advocates to enhance HIV/STBBI testing and care. These include promoting ethical practices in research, expanding testing options, increasing educational efforts, and offering culturally sensitive services. By implementing these recommendations, stakeholders can address healthcare disparities, reduce stigma, and improve health outcomes for these communities.

In essence, the Ubuntu-Pamoja study calls for a unified effort to create a more equitable and effective health system that respects and meets the unique needs of African, Caribbean and Black communities. By fostering an environment of trust, transparency, and inclusivity, we can empower individuals to take control of their health and build a healthier, more inclusive future for African, Caribbean and Black communities in Manitoba.

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The Ubuntu-Pamoja study is a collaboration between community members, service provider agencies, and University of Manitoba. For more information on this study, please visit:

villagelab.ca/ubuntu-pamoja

or email:

villagelab@umanitoba.ca