

# CHANGE THE NAME END THE STIGMA.

## EPIDEMIC OF THE MIND

AN EXAMINATION OF THE SOCIAL,  
CULTURAL, AND POLITICAL FACTORS  
PREVENTING THE WORLD FROM  
ENDING THE HIV EPIDEMIC BY 2030.

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# THEORETICAL BACKGROUND

INTRODUCTION

## EPIDEMIC OF THE MIND

“We have learned from the HIV epidemic that an epidemic isn’t just a health issue. It is more than just health. It is about communities, it is about the whole of society, it’s about economy, it’s about vulnerabilities and inequalities.”

Winnie Byanyima, Executive Director of UNAIDS (UNAIDS, 2020)

# A Global Perspective on HIV Today

In 2021, 38.4 million people were living with HIV worldwide, 650,000 of whom passed away in the same year following AIDS-related illnesses. Since the beginning of the HIV epidemic around forty years ago, 79.3 million people have become infected with HIV and the virus has cost the lives of 36.3 million people. New infections peaked in 1997 and have since been reduced by 52% to 1.5 million new infections of HIV in 2020. (UNAIDS, 2021)

To this day, the AIDS epidemic continues to affect every country in the world. It challenges health systems, the development of countries, human rights and poses an immense social challenge. (United Nations, 2021) In many countries, HIV testing, diagnosis, and treatment were interrupted by responses to the 2020 breakout of the COVID-19 pandemic, such as lockdowns and compulsory isolation. In some countries the disruption of medical supply chains was as high as 75%. (UNAIDS, 2021; Stover, 2021) Reduced capacity and the fear of infection drove many people away from health care facilities. (Stover, 2021) There was no supply of vaccines for most people living with HIV (PLHIV) who were additionally predisposed to a more severe course of the disease and higher comorbidities. (UNAIDS, 2021) Over the course of the following two years, reimposed lockdown restrictions and other factors have prevented a stable continuation of global HIV care and support. (Stover, 2021) COVID-19 was an immense setback in the global effort against HIV and continues to reinforce existing inequalities in treatment and health care access. (United Nations, 2021)

In 2020, the UNAIDS targets for that year were not met. Every new infection and every new AIDS-related death is taking place with knowledge and tools available that could have prevented them. (United Nations, 2021) There are still around 10.2 million PLHIV who are not accessing treatment globally. Of these 10.2 million, about 4.1 million were unaware of their HIV positive status and 6.1 million were aware of their status but were unable or unwilling to access treatment. (UNAIDS, 2021) These are the people who need to be reached in order to prevent the further spread of the virus. While treatment progress is being made globally, there has been little reduction in the number of new infections over the past four years. We must thus ask what factors are causing people to not seek or not be able to seek care.

# Barriers to Accessing Health Care

Having access to health care is often understood as insurance coverage. But this does not do justice to the numerous factors that impact people's actual access to health care services. (Garney, 2021) Health care availability does not automatically equate to health care accessibility. Patients encounter numerous barriers when seeking health care, and we can observe immense inequalities in how these barriers affect different populations within and between countries. (Dawkins, 2021)

A global problem requires a global solution, but we are confronted with a great heterogeneity of societies and cultures. Individual groups must therefore be met at the level of their individual barriers.

One approach that has proven successful in addressing local and cultural health care access barriers is community-based work. Involving people living with HIV (PLHIV) in efforts to address HIV has led to increased testing uptake, promoted affordability and greater access to medication, influenced policymaking and other benefits. It has also helped to start new conversations around stigmatization, inequalities, and discrimination. As members of their community, PLHIV have a greater understanding of an individual's situation-specific needs and challenges. This contributes to the effectiveness of community-based work.

The more knowledge on the topic is shared and made available, the fewer HIV infections will occur. That new HIV infections and AIDS-related deaths are a phenomenon driven by social, cultural, and political forces is something the global HIV effort should use to its advantage.

Our research is focused on achieving a better understanding of these forces in order to find an actionable global solution that can be flexibly applied to enhance HIV prevention and treatment strategies across different cultures, communities, and geographies. The research focuses on five key social, cultural, and political factors:

## **Awareness and Knowledge:**

Sexual-health knowledge determines an individual's sexual risk behavior. Sexual education increases the use of preventive HIV measures, testing uptake and therapy compliance, and reduces the stigmatization of PLHIV. However, a decisive lack of access to sexual-health education is a reality in many parts of the

world. Individuals can be prevented from accessing adequate sexual-health knowledge by different factors depending on their background, gender, and socioeconomic status.

## **Stigma and Discrimination:**

Stigmatization and discrimination assert the assumption that being seropositive is equivalent to dying biologically and socially. This can cause people with HIV to keep their diagnosis hidden for fear of social rejection. When public stigma is internalized, it makes people less likely to seek out care and sexual-health services, putting them at a higher risk of unintended pregnancy and sexually transmitted infections (STIs). Stigma is also a barrier to health care. It can cause the outright denial of care or the provision of substandard care, physical and verbal abuse, and longer wait times, to list just a few issues.

## **Availability:**

Higher HIV service availability leads to reduced viral transmission and death rates. It also substantially reduces health care expenses. Globally, 6.1 million people who are aware of their HIV-positive status are not being treated. HIV-associated health services shouldn't stop with the provision of adequate HIV medication. The availability of education, contraception, and social care is crucial to ending the epidemic as well.

## **Gender Equality:**

Gender norms often lead to unsafe sex. Around one in three women globally are affected by gender-based violence at least once in their lifetime, primarily perpetrated by intimate partners. This is especially the case for key populations affected by HIV, notably female sex workers, transgender women, and women who use drugs. This gender-based violence can lead to a lower quality of health care and an overall higher vulnerability to some diseases. This system undermines women's health and promotes marginalization of and discrimination against all those who do not fit within society's restrictive gender norms.

**Spirituality:**

Religion and sexuality are often placed on opposite sides of the moral spectrum. But in some cases, religious beliefs within communities prevent individuals from seeking or accessing adequate health care. This may be due to medical practices such as blood transfusion, vaccination, and contraception being perceived as unacceptable, with prayer being the preferred method of action. However, spirituality and religion cannot be dismissed when looking to provide quality health care services. They play major roles in bringing a positive effect to people's quality of life and their health-care-seeking behavior.

These factors have been described as having both enabling and disabling influences on health care access in previous studies and findings.

HIV today is an "Epidemic of the Mind". The tools and knowledge to prevent new HIV infections and AIDS-related deaths are already available. It's not medicine holding us back: We have the scientific understanding of HIV to prevent new infections and reach the 2030 UN Development Goal of ending HIV/AIDS as a global public health threat by 2030.

Current new infections and AIDS-related deaths are driven by social, cultural, and political forces that must be effectively addressed if we are to achieve the 2030 development goal. This will require significantly updating and broadening the strategies on which the global HIV response is currently based.

This paper examines the influence of social, cultural, and political factors on individuals' access to HIV knowledge, testing, and treatment in the context of a quantitative research study. In the first step of the results below, we focus on research from Germany. In a second phase, the study will be extended to the USA and South Africa.

# LITERATURE REVIEW



## STIs in Numbers

In 2020, approximately 91,400 individuals with HIV were living in Germany, which translates to a prevalence of about 109.9 cases per 100,000 people. At 2000, new cases in 2020 are only slightly lower than the numbers reported in previous years. A steady trend shows a decrease in new cases involving men who have sex with men (MSM) and a clear increase in heterosexual and IVD groups since 2012. (an der Heiden M, 2021)

Within the 90-90-90 goals, Germany reached 90% treatment coverage by 2011, and since 2020 has reached all three goals with current treatment success rates being at 96%. (an der Heiden M, 2021) Pre-Exposure Prophylaxis (PrEP) has been free in Germany since the beginning of 2019 for individuals who have public health insurance. The drug has also been available to the public via prescriptions since its approval by the European Medicines Agency (EMA) in 2016.

Current estimates suggest there are between 15,600 and 21,600 individuals who take PrEP on a regular basis. There is no reliable available data on the use of Post-Exposure Prophylaxis (PEP).

Meanwhile, other STIs are on the rise in Germany. Most notably, new syphilis infections have tripled every year since 2008 to a total of 7,921 cases in 2019 or 9.5 cases per 100,000 people. (Rasokat, 2021) There are no nationwide statistics on STIs other than HIV and syphilis in Germany. However, in 2020, chlamydia infections are estimated to be around 300,000, and gonorrhea around 30,000. (BZgA, 2021; Deutsche STI-Gesellschaft e.V. [DSTIG] – Gesellschaft zur Förderung der Sexuellen Gesundheit, 2019)

## Youth

Since 1980, Germany's Federal Centre for Health Education (BZgA) has launched regular large-scale reports on the sexual behavior of minors and young adults. (Scharmanski S. &, 2021) This information allows us to build on an existing stock of data and view how certain aspects of sexual health and prevention function within Germany. (Scharmanski S. &, 2021) However, these reports usually lack depth in relevant questions. (Scharmanski S. &, 2021)

The most recent report from 2019 suggests that the share of heterosexual youth who had already had sexual intercourse stayed constant or even decreased. 10% of 15-year-old boys and 13% of 15-year-old girls reported having already experienced intercourse before. (Scharmanski S. &, 2021)

According to the report, 41% of 14- to 25-year-olds had been in a relationship. Of these, two-thirds reported this relationship to have lasted a year or more. Most participants (75% of females, 62% of males) indicated that loyalty and sexual exclusivity are requisites for a relationship. (Scharmanski S. &, 2021) The most used channels for gathering information on sexual intercourse and sexual health among youth were reported to be teachers (36%–38%), a best friend (39%–45%), a father

(27%–45%) and same-gender peers (22%–32%) for male participants and teachers (33%–35%), a best friend (49%–55%), a mother (43%–70%) and same gender peers (19%–24%) for female participants. A particularly unpopular source for information were physicians (12% of females, 2% of males) and partners (11%–12% of females, 11%–16% of males). (BZgA, 2020) (Scharmanski S. &, 2021)

A different study conducted with youth in Germany indicates a high awareness of HIV (97.8%), as well as syphilis, chlamydia, gonorrhea, herpes, and hepatitis B (all over 75%) and significantly lower awareness for trichomonas, HPV, and mycoplasma (all under 65%). (Skaletz-Rorowski, 2021) The same study found that while a majority of participants (59.9%) had tested for HIV previously, only 39.7%, 20.6%, and 21.3% had been tested for chlamydia, gonorrhea, and syphilis, respectively. Additionally, only 58.5% were aware that condoms do not prevent all sexually transmitted infections. (Skaletz-Rorowski, 2021)

# The STI Health Service Situation in Germany

The German guideline for the treatment of sexually transmitted diseases stipulates that treatment providers should have the relevant knowledge, as well as psychosocial understanding and communication skills. (1) However, in Germany, the treatment of STIs is not assigned to a specific specialist. Unlike in other countries, the provision of medical services for the prevention and treatment of sexually transmitted diseases is spread across various disciplines. These include dermatology, general practitioners, gynecologists, urologists, and various specialized facilities that often specialize in a specific target group, such as MSM. (Schmidt, 2011)

However, a great deal of coverage, especially in the area of prevention, is also provided by social workers, public health officers, and other points of contact that are not directly located in a medical facility. Although strengths can be attributed to this broad positioning, it is often difficult for patients and individuals at particular risk to navigate this jungle of medical disciplines and care contact points. The question of health insurance coverage arises in the case of medical facilities, as do issues of anonymity and responsibility. Particularly large disparities are evident in sexual health services here in the areas of prevention and treatment. (Deutsche STI-Gesellschaft e.V. [DSTIG] – Gesellschaft zur Förderung der Sexuellen Gesundheit, 2019)

Individuals who want to receive PrEP must have a medical exam and risk assessment before receiving the drug. If it is prescribed, the cost of the treatment is covered by the patient's statutory health insurance. (Uhrmacher, 2022) When it comes to statutory health insurance coverage of STI screenings, only individuals on PrEP or women under the age of 25 who qualify for a chlamydia screening, are covered. The costs of other

services quickly rise above EUR 200 (Müller, 2022), a problematic or even insurmountable burden for many individuals. For precisely this reason, numerous points of contact have been established, such as NGOs or local health centres, that offer affordable STI screenings. However, in the event of a positive test, these organizations are not able to provide medication or treatment as this requires certification and approval from the German Federal Institute for Drug and Medical Devices (BfArM) (Müller 2022). Again, this gap between testing and treatment access presents a barrier for many individuals to seek adequate medical services.

The German guidelines are full of ambitious guiding principles. They include routine questioning about sexual history by the practitioner, vaccination against HPV and HBV for all adolescents and young adults, and annual chlamydia screenings. (2) However, as illustrated by the above-cited demographic data on awareness of these viruses, reality differs significantly from these guidelines.

A hallmark of many STIs is their asymptomatic nature. A significant proportion of STIs thus remain undetected and serve as a reservoir for further transmission. Moreover, untreated STIs may eventually result in serious long-term sequelae. (8–12). In Germany in 2018, around 12% of PLHIV were estimated to be unaware of their HIV infection. At the time of diagnosis, one-third of individuals had CD4 counts below 200 cells/ $\mu$ l or AIDS. (7) Put simply, a third of all people diagnosed with HIV in Germany already had a transmittable viral load of which they were unaware. To tackle the problem of asymptomatic infections, medical guidelines recommend STI testing for asymptomatic persons at risk. (13)

## Implication

HIV and other STI infection rates have stagnated in some German demographics and increased in others. This trend away from an across-the-board decrease in new infections suggests new frameworks for addressing sexual health should be considered. Previous research into the behavior of youth in regard to sexuality and sexual health reveals several blind spots worthy of further investigation.

As stated, our research focuses on five key factors influencing sexual health and access to sexual health care. Current available data allows us to deeply consider the factors of awareness and knowledge, and availability. Stigma and discrimination, gender inequality, and spirituality are less well-represented in the available data, however, we will conduct our own research to investigate these as contributing factors.

# PRESENTATION OF OUR RESEARCH

METHODOLOGY

## Study Design

Our research was based on a prospective (cross-sectional) study design that aims to accurately characterize access to the health system regarding sexual health and HIV/AIDS topics. The collection of information has been done by using a standardized multiple-choice questionnaire accompanied by an open-text passage question. Sociodemographic

questions are consulted, as well as specific questions about visits to health services. Our objective was to analyze all the factors that influence access to the health system in order to derive courses of action to address them. The study was conducted between June 2022 and October 2022 in Germany.

## Participants: Study Subjects

Our target group consisted of women and men between the ages of 16 and 24 from Germany. For both the quantitative and qualitative components of the research, we interviewed health care experts in the field of sexual health and HIV/AIDS.

## Data Collection

The research data was collected via anonymous standardized questionnaires that included questions about sociodemographic characteristics, sexuality, and experiences relating to access to health services. Out of 25 questions, 24 offered multiple-choice answers, and one was an open question. The questionnaire was filled out by 969 people, out of whom 920 were under 18 years old and 49 were over 18 years old.

## Questionnaire Design

The survey was designed in a multiple-choice format and written in an unbiased and non-persuasive language based on previous studies in the fields of health care and youth STI prevention. Questions focusing on societal and structural access barriers to the aforementioned services were chosen for the study. Additionally, questions targeting individual factors influencing access to health care and prevention services were asked. The questionnaire was reviewed by external sexual health experts to ensure validity and test reliability.

An anonymous cross-sectional survey was conducted from June 2022 to October 2022. The questionnaire was written in German. The research framework was built on evaluating the current access barriers regarding sexual prevention and health care services for youth in Germany. Special attention was given to ensuring the delimitation between societal, structural, and individual factors.

Questions about access were designed in order to gain precise insights into our study group's interactions with the health care system. The descriptive and inductive evaluations were created with the statistical program package SPSS Statistics 28.0. (IBM, 2021)

## Early Findings

This study was conducted to determine the barriers adolescents face when accessing sexual health care services in Germany. In order to determine the needs of different subgroups, the study population was split into participants aged 18 and above (Group A) and participants younger than age 18 (Group B).

Group A consisted of 26 male participants (53.1%), 22 female participants (44.9%), and one diverse participant (2.04%). The mean age of Group A was 19.71 years old. Of all Group A participants, 39 identified as heterosexual (84.8%), 4 as bi-/pansexual (8.7%), and 3 did not want to share their sexuality (6.5%).

Group B consisted of 438 male participants (48.24%), 462 female participants (50.88%), and 8 diverse participants (0.88%). The mean age of Group B was 15.85 years. Of all Group B participants, 760 identified as heterosexual (83.7%), 9 as homosexual (1%), 89 as bi-/pansexual (9.8%), 10 as asexual (1.1%), 6 as other (0.7%), and 34 did not want to share their sexuality (3.7%).

	Group A (18+)	Group B (<18)
<b>Total number of participants</b>	49	908
Number of male participants	26 (53.1%)	438 (48.24%)
Number of female participants	22 (44.9%)	462 (50.88%)
Number of diverse participants	1 (2.04%)	8 (0.88%)
Mean age	19.71 years	15.85 years
Number of heterosexual participants	39 (84.8%)	760 (83.7%)
Number of bi-/pansexual participants	4 (8.7%)	89 (9.8%)
Number of homosexual participants	0 (0.0%)	9 (1%)
Number of asexual participants	0 (0.0%)	10 (1.1%)
Number of participants with other sexuality	0 (0.0%)	6 (0.7%)
Number of participants not willing to share their sexuality	3 (6.5%)	34 (3.7%)

Table 1: Demographic Data of Study Participants

As established in the previous section on the structure of health and sexual health services in Germany, individuals can find it challenging to navigate the complexities of the health care system. To determine if adolescents are aware of service offers, the participants were asked if they knew where to access HIV and STI testing. Of all Group A participants, 55.1% were not aware of where they could access HIV testing. 59.2% were aware of where they could go to get tested for STIs. The awareness in participants younger than age 18 was even lower: of all Group B participants, 65.5% did not know where to get tested for HIV and 75.7% were not aware of where they could get tested for STIs. Our future research will further investigate the awareness of different services among these demographics.

The way sexual health services are spread among a wide range of medical disciplines in Germany makes this a particularly pertinent topic. Even in one of Europe's richest countries, a significant portion of people's sexual health is endangered because they do not understand how to navigate the bureaucracy of different medical disciplines and insurance. On the topic of service point awareness, participants were asked what type of professional they would consult if they suspected they had contracted an STI.

Among both groups, gynecology was named the most often (51.0% of Group A participants and 48.2% of Group B participants), and in second place was family medicine (46.9% of Group A participants and 41.7% of Group B participants). At least 15% of both groups named urologists and general practitioners as professionals they would consult (Group A urology 24.5%, Group B urology 21.1%, Group A general practitioner 18.4%, Group B general practitioner 22.4%). Other options, including dermatology, consultation, emergency room, pharmacist, social worker, and "other", were chosen by less than 10% of Group A and Group B participants. Exact data can be found in Graph 1.

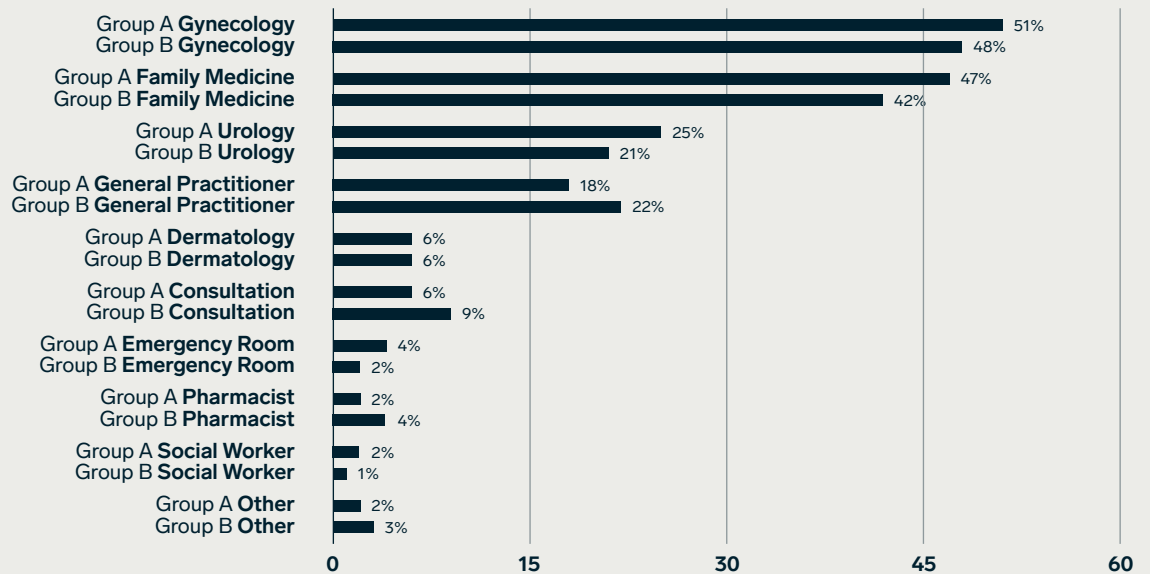
To investigate the different factors that prevent adolescents from accessing sexual health services, study participants were asked about reasons for not using them. Among Group A participants, 51.0% saw no need for taking up sexual health services because they did not see themselves as at risk. In Group B, 48.7% cited the same reason for not taking up services.

Among Group A participants, 10.2% stated they did not know where to go to access sexual health services. The same applied for 12.6% of Group B participants. Other reasons that were given included services being too expensive (Group A 8.2%, Group B 5.5%), fear of parents knowing (Group A 6.1%, Group B 7.3%), shame (Group A 4.1%, Group B 6.2%), insecurity about sexual orientation (Group A 2.0%, Group B 3.5%), and faith and religion (Group A 2.0%, Group B 2.8%). Reasons that were only reported by participants younger than 18 years old (Group B) included services being too far away (2.7%), insecurity about sexual identity (2.5%), and fear of stigma and discrimination (2.3%). An overview of these results is given in Graph 2.

In our future research we will further explore structural barriers such as waiting times for appointments, the preferred opening hours of practitioners, and the financial implications of testing and treatment services. Part of this in-depth assessment included asking respondents about negative experiences they encountered when accessing sexual health services. Of all Group A participants 8.2% reported encountering stigmatization and discrimination, 4.1% reported a lack of sexual health care facilities in their city or town, and 14.3% reported experiences where providers displayed a negative attitude towards them. Respectively, 2.7% of Group B participants reported experiences with stigmatization and discrimination, 3.3% reported a lack of sexual health care facilities in their city or town, and 7.9% reported experiences with negative attitude from their providers.

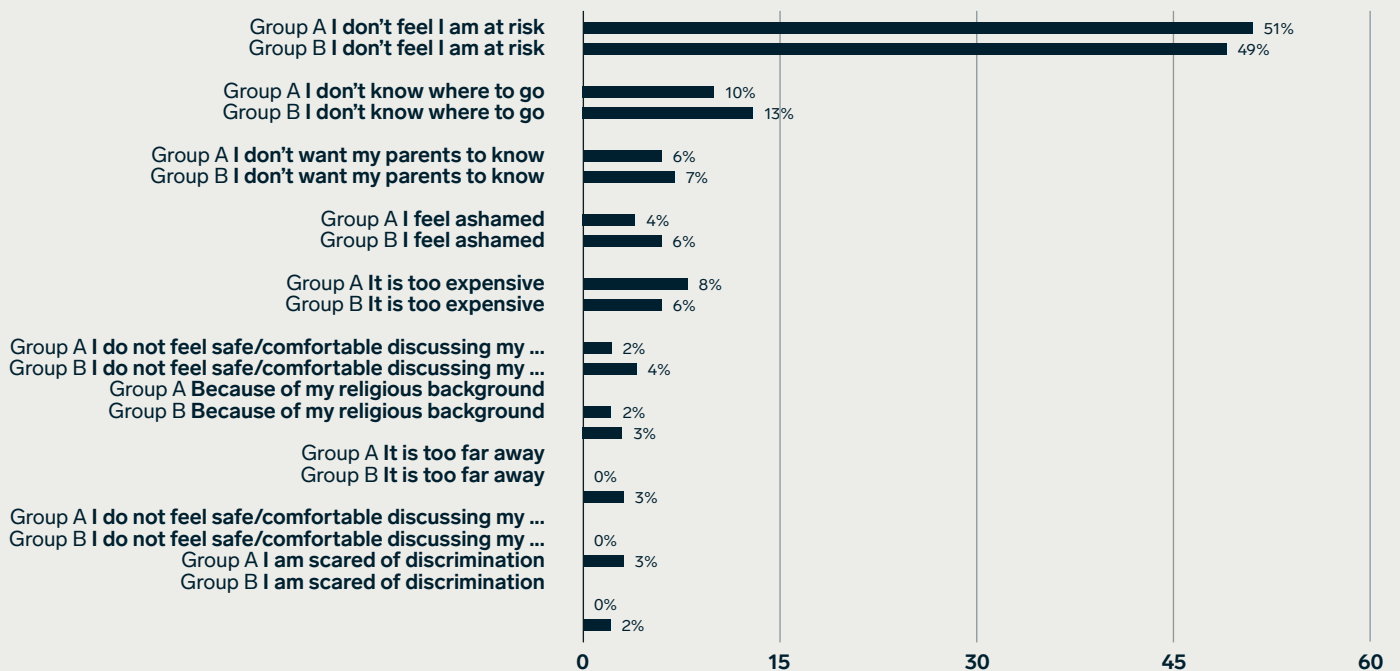
To gain a more holistic understanding, our future research will include an assessment of what service points adolescents have successfully taken up, the regularity at which participants are seeking sexual health services, as well as difficulties they had encountered when accessing contraception and HIV and STI testing. This will also include an assessment of their knowledge of PrEP and PEP.

What type of professional would you consult in the suspension of an STI?



Graph 1: Types of profession adolescents of 18 years old and older (Group A) and younger than 18 years (Group B) would consult in case of suspicion of an STI

What are the reasons for not using sexual health services?



Graph 2: Reasons for adolescents of 18 years old and older (Group A) and younger than 18 years (Group B) to not take up sexual health service

## Discussion

Five factors have been recognized by us as key to impacting the fight against HIV/AIDS and improving the sexual health journey of individuals within health care systems. We acknowledge the difficulty behind challenging these five factors. However, addressing these barriers is a key step in allowing people to better adhere to a happy, healthy sex life.

The early findings of our research have encouraged us to continue working with youth. Participant responses to the question “Which professional would you go to if you suspected you had contracted an STI?” were particularly interesting and deserve further research.

When faced with the above question, participants had the chance to choose as many answers as they considered convenient. 48.2% of participants in Group B answered that they would go to gynecologist, followed by 41.7% to family doctor, and 22.4% to general physician. For participants in Group A 51% answered that they would go to gynecologist, followed by 46.9% to family doctor, and 24.5% to urologist.

These answers are important to understand in the context of Germany, where the provision of medical services for the prevention and treatment of sexually transmitted diseases is spread across various disciplines. Prevention is provided by social workers, public health officers, and other points of contact that are not directly located in a medical facility. This can be seen as a strength or weakness of the German health care system. However, the high number of various prevention specialists creates a challenge for individuals who do not know which specialist to approach in which situation.

Our next question was posed to find out if participants knew where to access sexual health services, in which 54.7% of the participants in Group B answered that they knew where to find condoms, 48.9% knew where to find the service point for contraceptives, and 41.3% had knowledge about a general awareness consultation. It is important to mention that only 34.5% and 24.3% knew where to access the service points for HIV and STIs, respectively.

44.9% of participants in Group B answered that they knew where to find condoms, and in contrast to participants in Group B, 44.9% knew where to access the service point for HIV and 40.8% for STIs. As for the knowledge about service points for contraception and general awareness, it was 32.7% and 36.7%, respectively.

It is interesting to put these results in contrast to other studies, as most participants (59.9%) had tested for HIV previously, only 39.7%, 20.6% and 21.3% had been tested for chlamydia, gonorrhea, and syphilis respectively, highlighting a greater knowledge around HIV and an underestimation of STIs.

When asked about what reasons participants had for not using sexual health services, the most prevalent answer in both groups, with 48.7% in participants in Group B and 51% in Group A, was that they did not have risk perception, followed by 12.6% in Group B and 10.2% in Group A stating that they did not know where to go.

Our previously recognized challenge of preventing the spread of STIs by addressing and challenging the five key factors is represented here, with the participants' low-risk perception and lack of knowledge on where to seek sexual health services even when they wanted to.

When asked about situations they had found themselves in when searching for, or using sexual health services, both groups mentioned situations where they experienced: a sexual health service provider's negative attitude, inappropriate language, or stigma and discrimination.



## In Conclusion

Our findings highlight the relevance of researching and discussing barriers to modern health care. As a society, we need to recognize that available health care does not necessarily equate to accessible health care. Inequalities in our world form barriers, preventing people from reaching accessible and equitable health care.

We will continue our holistic research approach by examining factors such as Awareness and Knowledge, Stigma and Discrimination, Availability, Gender Equality, and Spirituality. The next steps in our research will investigate how these key factors are perpetuating STIs like HIV in the USA and South Africa.

At this stage, prevention through protection and education is key – Germany is (still) seemingly unable to integrate a reasonable dialog around STI prevention into the education of its young adults. To stop the spread of the virus, our primary target should be to begin a new and open dialog with a generation where sexual freedom is on the rise once again.

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