Key Populations' Values and Preferences for HIV, Hepatitis, and STI Services:

A Qualitative Study

GATE

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About GATE

GATE is an international advocacy organization working towards justice and equality for trans, gender diverse and intersex communities. Rooted in our movements, we work collaboratively with strategic partners at the global level to provide knowledge, resources and access to international institutions and processes. Our vision is a world free from human rights violations based on gender identity, gender expression and sex characteristics. Our strategy is to transform the landscape of global advocacy, knowledge creation and resource distribution through critical inclusion of trans, gender diverse and intersex movements at all levels of political, legal and socio-economic processes.

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Introduction

Trans and gender diverse (TGD) people are individuals who identify themselves with a different gender than the one they were assigned at birth. TGD people have all kinds of gender identities, such as for example trans women, trans men, trans non-binary.

TGD people are considered a key population specifically vulnerable to HIV that bear a disproportionate burden of global HIV infections. TGD people are 13 times more likely to acquire HIV compared to the general population[1]. Specifically, transfeminine people are strongly affected by this epidemic[2]. Transmasculine people are, to date, under-researched, but studies have shown 3%[3]- 38%[4] prevalence in this population. To date there is no data available about HIV prevalence in trans non-binary people.

Inadequate inclusion in data collection makes it difficult to understand the lived realities of TGD people in general. Across different geographical and cultural regions, there are a wide variety of lived realities and experiences within this community. The differences in country legislations regarding legal gender recognition and, in some cases, criminalization of TGD individuals, may impact access to HIV/STI prevention, services, treatment, and care. The individual experiences across different country settings, and the diversity of TGD people's self-identification and bodily diversity present this community with unique needs and vulnerabilities regarding HIV, hepatitis and other STIs.

GATE conducted a qualitative study among global TGD community members to shed light on these needs and vulnerabilities, and to understand the values and preferences regarding HIV, hepatitis, and STI services. This qualitative study was done in close collaboration with the World Health Organization (WHO) and with other key population networks of gay and bisexual men and other men who have sex with men, sex workers, and people who inject drugs. The community-lead organizations conducting similar qualitative studies within their communities were: International Network of People Who Use Drugs (INPUD), MPact Action for Gay Men's Health and Rights (MPact), and the Global Network of Sex Work Projects (NSWP).

Based on the outcomes of these studies, the WHO's 2016 Consolidated Guidelines for HIV Prevention, Diagnosis, Treatment, and Care for Key Populations[5] will be updated by the WHO-convened Guidelines Development Group.

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1 WHO, 2021 "Transgender People".

2 WHO, 2021 "Transgender People".

3 Becasen J et al., 2019 "Estimating the prevalence of HIV and sexual behaviors among the US transgender population: a systematic review and meta-analysis 2006-2017". American Journal of Public Health 109(1):e1-e8.

4 Kloek M et al., 2020 "HIV prevalence and risk in male, trans male, and trans female sex workers in Zimbabwe". Abstract 879. Conference on Retroviruses and Opportunistic Infections. March 8-11, 2020.

5 World Health Organization, 2016, "Consolidated Guidelines on HIV prevention, diagnosis, treatment and care for key populations: 2016 update".

Methods and Study Design

Between May-June 2021 GATE conducted 10 semi-structured key informant interviews (KII) and 10 focus group discussions (FGD) with trans and gender-diverse (TGD) participants. Five sessions were conducted in English, three in Spanish and two in Russian. The core interview questions were developed in collaboration with the other key population networks and were then tailored by GATE to TGD needs and lived realities. All five WHO regions were included, and the interviews were conducted by GATE's principal investigators Max Appenroth and Erika Castellanos alongside four regional consultants.

The KIIs were conducted with local community leaders and FGDs were conducted with trans and gender-diverse individuals with mixed expertise in the field of HIV. All participants identified either as transfeminine, transmasculine, or trans non-binary, and were 18 years or older. KII participants were nominated by GATE staff and the regional consultants. For participation in the FGDs, GATE reached out to TGD community members via mailing lists, social media, local/regional TGD organizations, and community leaders. Interested individuals were asked to fill out a Google form to indicate their gender identity, country, level of expertise in the field of HIV/STIs, and preferred language for the interview. Participants were selected to achieve a balance of regional representation, gender identity, and expertise. However, not all selected participants ended up taking part in the FGDs.

Prior to the interview, participants were provided with information about the study and its aim. Additionally, they received a consent form. Consent was then given verbally by all participants at the start of the interview.

This study was approved by the WHO Research Ethics Review Committee.

Participant Demographics

A total of 50 participants were included in this study. Two thirds of the participants (n=33; 66%) identified on the transfeminine spectrum (i.e., trans women), 14 (28%) identified as transmasculine (i.e., trans men), and 3 (6%) identified as trans non-binary.

Participants were located in 29 different countries, including 24 low- and middle-income countries (LMIC) and 5 high-income countries (HIC)[6]. Proportionately, the majority of participants (42) were from LMIC and 8 participants were from HIC.

6 World Bank Databank, World Bank.

Table 1: Participants by Region

Region	Africa	Asia-Pacific	Europe (incl. Central Asia)	Latin America	North America and Caribbean
Participants	22% (n=11)	18% (n=9)	28% (n=14)	24% (n=12)	8% (n=4)

Results

Trans and Gender Diverse People's Health Priorities

Decriminalization of gender diversity, legal gender recognition, access to general and, particularly, gender affirming healthcare and mental health services, and community empowerment to deliver trans-lead services were most commonly associated with better (sexual) health outcomes and reduced risk of HIV/STI/HCV exposure. These topics recurred throughout all KIIs and FGDs, with participants highlighting the need for more accessible services globally.

Perceptions of Behavioural Interventions and their Impacts

Participants reported a variety of reasons for elevated risk of HIV exposure for trans and gender diverse people. Risk of HIV acquisition was most commonly associated with structural barriers for trans people accessing healthcare, including sexual health services, and finding employment in the formal job market. The lack of formal employment opportunities can sometimes drive some trans people to engage in sex work as their only resource for generating an income. Some trans people receive affirmation in their gender identity through relationships and with sexual contacts with people that might request unsafe sexual practices.

> **"I do not think that we chose to engage in high-risk behaviours, it is a series of structural violations that expose us to situations that place us at risk."**
> **Transfeminine participant, Colombia**

Additionally, a lack of education around HIV and other STIs, as well as a general lack of formal education and illiteracy in trans communities aggravates the situation for this community. Educational resources must be made accessible with regards to language being used (professional terminology might not be understood; terms used to describe body parts or sexual practices might not be in accordance with the bodily diversity of trans people's realities, etc.).

The most common answer to what behavioural interventions could lower the risk for HIV infection was access to legal gender recognition to reduce stigma and discrimination throughout the life continuance. Furthermore, improving access to healthcare for gender diverse people, specifically gender affirming care, and to sexual health services (especially HIV/STI testing) and HIV prevention (i.e., condoms, PrEP) must be prioritized to reduce risks associated with HIV and STI exposure.

> **"Find ways - alternative sustainable income sources to commercial sex work for trans people - all this coupled with health education to be able to self-assess risk vs benefit and, finally, access to proper gender affirming healthcare."**
> **Transfeminine participant, USA**

Additionally, access to coherent, community-targeted HIV and STI education and information is needed.

The impact of behavioural interventions on reducing harms associated with chemsex (PICO Q.1)

Throughout all KIIs and FGDs with trans people, chemsex was mainly associated with engagement in sex work. Specific concerns were also raised with regard to younger trans populations (16-25 years), trans MSM, and the rise of drug use outside of sexual contexts.
For various reasons (some self-chosen, but mostly due to transphobic societal structures), trans people are more likely to engage in sex work. To enhance performance and endurance, or to receive more clients in shorter periods of time, or to simply 'feel better' while working, trans participants reported high levels of drug use (i.e., crystal meth, heroin, etc.).
Often, clients would offer more money for sex under the influence of substances, which, for trans people engaged in sex work, poses a risk of starting to use drugs due to the opportunity to earn a higher income.

> **"At first you enjoy it, you see it as a game. But then you forget that you have a life of your own, your own love, and you only think of a drug in one shot. I speak of my situation, it's very difficult. For me it was just working to get high."**
> **Transfeminine participant, Mexico**

Trans people expressed much concern with regard to HIV/STI acquisition through shared injection materials (i.e., with clients) and through elevated risk behaviours under the influence of substances. Additionally, respondents across all regions described a lack of prevention campaigns, addiction support groups, resources, and alternative 'safer use' options targeted specifically at trans people.

Participants reported awareness and support programs for cisgender MSM in some regions, but those programs fail to address the specific vulnerabilities and needs of the trans community. In particular, trans MSM are not included in such programs, although they engage in sexual activities in high-risk networks.

> **"There are initiatives for MSM, but under a cis perspective ignoring [that] trans men are at risk too. Services are underfunded and not exactly trans sensitized."**
> **Transmasculine participant, UK**

> **"There should be more education around staying safe when using in order be able to make informed decisions." Transfeminine participant, USA**

The needs of trans people regarding chemsex are to reduce access barriers and discrimination in formal job opportunities, access to education around (safer) substance use and addiction, and access to safe and clean injection supplies.

Modes of Service Delivery for HIV, STIs, and HCV

Perceptions of peer navigators and their impacts on initiation and retention in treatment and prevention programmes (PICO Q.3)

Overall, respondents expressed a strong belief that peer navigators would improve access to testing, HIV prevention, initiation and continuation of HIV treatment.

> **"Definitely, yes, peer counsellors can improve program engagement and continuity. There should be consultants of different ages to reach trans people of different ages."**
> **Transmasculine participant, Belarus**

"It would be ideal for someone from the community to inform and help, that will prevent institutional violence [towards trans people]."
Transfeminine participant, Argentina

> **"Navigating sexual health is very different between different age groups [...]. Intergenerational learning exchanges are key."**
> **Transmasculine participant, Aotearoa/New Zealand**

Receiving information and sexual health education from peers who potentially have shared experiences, was described as effective and valuable. This is the case, especially during the COVID-19 pandemic, in which care seeking may be delayed, or accessing healthcare in general might be more difficult, community-based outreach at places where trans people meet (i.e., through street work) might improve testing, HIV prevention and treatment.

> **"The community peers have realities close to that of the community [they work with], such as sex work or living [with] HIV, and it makes them understand the trans reality."**
> **Transmasculine participant, Colombia**

However, concerns were also expressed about the lack of funding for such opportunities. Most peer navigators work on a voluntary basis or receive very little compensation for their efforts, which might hinder trans people from acting as peer navigators, as they generally already have a hard time in generating an income. Additionally, confidentiality issues were raised that, if trans community members act as peer navigators, they may spread confidential information in their networks.

The impacts of peer-lead services

Having trans-lead facilities and sexual health services would lower the barriers for TGD people to access much-needed care. Similar to peer navigators, such places can improve access to testing, HIV prevention, initiation, and retention in HIV treatment and care. Having trans people in leadership and educational positions were seen as acts of empowerment.

> **"Trans people in leadership positions may surround themselves with cis teams, but they will be the filter that reaches the trans community."**
> **Transfeminine participant, USA**

Respondents referred to "one-stop" options, where trans people receive not only sexual health care, but also gender affirming care. Integrating sexual health services into gender-affirming care, specifically delivered by knowledgeable, trained, trans-identified staff, was described as key to a holistic care approach that would improve the current negative situation of trans people regarding HIV and STIs.

> **"It would go a long way if trans people would offer services to the community."**
> **Transmasculine participant, Nigeria**

Collaboration between 'regular' healthcare facilities and trans-led clinics were described as effective, but additionally, trans people should be able to use any clinic available.

"Peer-led services would be ideal as one wouldn't need to explain who you are and just explain the symptoms. But this can't be done in an isolated way. There has to be some sort of hybrid integration as it is a two-way interaction and co-existence [between general care facilities and trans-lead facilities]."
Transmasculine participant, UK

The impact of online services (PICO Q.4)

Online tools and services were described by participants as a good option to access 'hard to reach' populations (i.e., geographically), but as this depends on structural factors such as internet/data connectivity and costs for internet and technical devices, this could also be a limiting factor. However, in COVID-19 times, with limited options for care, it was described as "better than having nothing".

> **"It is not the same as in person, but between not doing it and being online, [it] is better."**
> **Transmasculine participant, Peru**

Offering both in-person and online services were described as a good way to reach a wide range of the community. Participants also pointed out the importance of face-to-face interaction, to build trust and experience empathy from providers.

With regard to making information and education around HIV and other STIs accessible, using online platforms (especially social media, such as Instagram and Facebook) was described as very effective. However, online educational resources must offer scientific/medical proof, as there is a great risk of misinformation.

Values and Preferences Surrounding HCV Testing and Treatment

Among all respondents, the lack of information and education around the risks and consequences of Hepatitis C infection was mentioned. To date, there are only a few prevention campaigns targeted at the trans community (USA only) and most trans people are completely unaware of Hep C.

Despite the lack of awareness and knowledge around Hep C, participants raised great concerns about the risk of infection for trans people (i.e., unsafe sexual practices, sharing needles for drugs, hormones, and silicone injections).

"There is no information available on this [Hep C]. We estimate 5% to 10% of the trans population is vulnerable to Hep C due to hormone needle sharing and sex work."
Transfeminine participant, Uganda

"Everything that can be cured is not so scary. There are overstated myths about the dangers of HIV but underestimated in terms of the danger of hepatitis C transmission. It's bad that the programs are fixated on HIV, although it would be necessary that the programs go side by side."
Transfeminine participant, Russia

Values and Preferences Surrounding STI Prevention, Testing, and Treatment

Participants broadly criticized the inaccessibility of HIV/STI testing for trans people. Except in Global North countries (Australia, UK and USA), respondents reported limited to no access to HIV/STI testing for trans and gender diverse participants. Where access was available, HIV testing was more accessible than testing for other STIs. In countries where testing is available to trans people, this service is mostly offered by NGOs, not by state/government health institutions. Those NGOs are mostly cisgender LGB-led organizations offering services to cisgender MSM, which, at times, may include trans identities in their services. However, even in NGO-lead testing facilities, trans people may be exposed to stereotypical assumptions about gender identity, bodies, and sexual practices, or even discrimination and violence.

"Doctors from friendly offices are poorly informed about trans people, trans people are faced with inappropriate questions and stigma, and are trying to reduce the number of visits."
Transmasculine participant, Russia

Often, testing is associated with high costs and given the poor socioeconomic position of trans and gender diverse people in most regions, this is another access barrier. Some countries (i.e., Kazakhstan) offer free testing to all citizens, but trans people are not recognized or recorded as trans and are listed as cisgender. Additionally, testing in hospitals or other cisgender-centred 'general' medical institutions comes with the risk for maltreatment, discrimination, and violence for trans people.

Generally, testing outside of bigger cities is not accessible for trans people and the cost of travelling to urban areas is a barrier to quality health access. Even if testing is available, respondents highlighted the problem that medical care and medication are widely inaccessible, in the case of a positive result.

The need for more funding for empowerment and implementation of trans-led sexual health clinics (or at least testing options) was mentioned throughout the majority of the interviews and discussions. Participants mentioned multiple times that HIV/STI testing and care could be integrated into gender affirming care.

Additionally, trans people need access to up-to-date and medically-sound information about HIV/STI risk in a language that is understood by and reflects the lived realities of the community. Medical staff in general need training on trans and gender diverse-competent STI and HIV care.

> **"One urgent need is an open mind from providers [regarding their] perspective around trans bodies, to understand differences between identity and anatomy." Transfeminine participant, USA**

HIV prevention methods and technologies

Broadly, HIV/STI prevention is not targeted to the specific needs and the diversity of the trans community. If prevention services are available, they are mainly offered to cisgender MSM, and at times may also include trans people (mostly trans women). However, those services often do not appropriately address or respect the identities of gender diverse people or reflect the lived realities of the TGD community.

PrEP is widely inaccessible for trans people due to a lack of rollout and general inaccessibility of (sexual) healthcare services. PrEP is associated with high costs and is often only accessible for cisgender MSM. The lack of information around PrEP, especially the lack of data about effectiveness in combination with gender affirming treatment such as gender affirming hormone treatment, was mentioned multiple times by participants from various regions.

PrEP and its different dosing regimens and modalities

So far, the only accessible PrEP option in most regions are pills (there is no access to PrEP in some countries i.e., Cambodia). The majority of participants have not heard of the Dapivirine Vaginal Ring and had limited knowledge around the injectable PrEP (some hadn't even heard of PrEP). Inaccessibility of PrEP was most commonly related to structural barriers and a significant lack of information about this drug within the trans community. Trans people at risk are often not aware about the existence of this drug and they are not appropriately informed by healthcare providers about it.

Many participants across all regions pointed out the lack of existing data on the efficacy of PrEP in trans bodies and the misinformation present in the community (i.e., that PrEP affects the effectiveness of hormones in the body).

Despite some voices of concern, the injectable PrEP option was most commonly referred to as the preferred modality, if made available. This is due to the fact that it limits the chance of forgetting to take the daily medication and reduces the risk for trans people of carrying around drugs that might expose them as vulnerable to HIV or even being falsely assumed of being HIV positive in front of authorities (i.e., when getting arrested for sex work, being trans, or any other reason). However, having to go back to see a medical provider regularly to receive the shots has been described as a limiting factor.

Some participants were not aware that, currently, an on-demand intake of PrEP is not recommended for trans people under gender affirming hormonal treatment and/or who underwent gender affirming genital surgery. Due to a lack of research, there is currently no sufficient proof of effectiveness in trans people undergoing gender affirming hormonal treatment or after gender affirming genital surgery.

Structural Barriers and Enabling Interventions

Impacts of stigma, discrimination, and criminalisation on access to services

Throughout all FGDs and KIIs, the lack of legal gender recognition (or structural barriers to accessing LGR in countries where such legislation exists) and criminalization of trans and gender diversity; criminalization of sex work and drug use; the lack of anti-discrimination policies and laws; high levels of stigma, discrimination and exclusion in all areas of life; barriers accessing education, work and safe housing; and excessive physical and sexual violence against trans and gender diverse people were associated with limited access to (sexual) healthcare services and elevated risk for HIV, STI, and HCV acquisition.

Enabling interventions

For participants, it was hard to single out one specific enabling intervention, as trans people are affected on so many levels by criminalization, stigma, discrimination, and violence, with community empowerment mentioned multiple times throughout all FGDs and KIIs as key to appropriate and respectful (sexual) healthcare.

"All of them are important, in particular community empowerment, to become informed, protective and strong to keep trans communities safe, free and equal." Transmasculine participant, Australia

"Once communities are empowered, they can become healthcare providers, they are trained and certified. That will eventually lead to access to employment and equal treatment." Transfeminine participant, Thailand

Discussion

The outcomes of this study highlight the need for tailored interventions and key values and preferences for trans and gender diverse (TGD) people. HIV, STI, and HCV services and prevention are widely inaccessible for this community. The data portrays the lived realities of trans and gender diverse people (TGD) on a wide geographical and cultural scope, yet the experiences of the TGD community are similar regardless of location.

TGD community members are aware about the risks for HIV infection and highlighted the structural barriers associated with these risks. Lack of access to education, formal employment, and housing are only some of the issues mentioned that present an increased vulnerability for new HIV infections. TGD people often have no other income opportunities other than sex work, which exposes them to even greater vulnerability, stigma, and discrimination. In addition, chemsex was often associated with being involved in the sex industry, putting TGD sex workers even at higher sexual health risk.

The prevalence of discrimination and stigma have been commonly reported by most participants. Discrimination and stigma are not only experienced in medical settings, with better sexual health associated with steps for more inclusion of trans and gender diversity on a wider societal level. In many countries TGD individuals fear prosecution and criminalization based on their gender identity, and most countries are lacking adequate frameworks for legal gender recognition procedures. Access to legal gender recognition has been found to improve the mental health of TGD people who wish to take this step in their transition[7]. In addition, access to medical gender affirmation (i.e., access to gender affirming hormones, surgeries, etc.) has been associated with higher uptake of HIV and STI testing, as well as awareness about PrEP in trans youth[8].

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7 Scheim, A. et al., 2020, "Gender-concordant identity documents and mental health among transgender adults in the USA: a cross-sectional study", The Lancet Public Health 5: e196-203.

8 Andrzejewski, J. et al., 2021, "Medical Gender Affirmation and HIV and Sexually Transmitted Disease Prevention in Transgender Youth: Results from the Survey of Today's Adolescent Relationships and Transitions, 2018", LGBT Health (8) 3: 181-189.

A recent systematic review and meta-analysis found lower rates of new HIV infections and better uptake of sexual health services in key populations[9]. Study participants reported that peer-led education and services delivered by community members are widely connected with better uptake and retention of HIV prevention, treatment, and care. However, lack of funds for peer-led initiatives, intervention, and capacity building and professionalization options for TGD community members are widely missing. Funders and policy makers need to include to promotion of TGD-led initiatives.

Online tools were seen as a welcome addition to in-person service delivery. Through online consultations, sexual health services are accessible to TGD community members in hard-to-reach regions. However, the study participants highlighted the need for personal interactions that should not be replaced by online services. Such services were also associated with certain barriers, as not all trans people have access to technical devices or internet/data to use online tools.

Information about viral hepatitis was widely inaccessible to study participants, and some were even not aware about HCV. There are currently no known hepatitis C prevention campaigns inclusive of, or even tailored to, the TGD community. Most participants reported that they are not aware of HCV testing in their region.

Lack of knowledge and inaccessibility of PrEP for TGD people was an additional outcome of this study. Where available, participants only had access to oral PrEP and based on current availability this was the preferred modality. Most participants have not even heard about other delivery options, but expressed their interest in the long-acting injectable PrEP, if made available.

Conclusion

Structural barriers, criminalization, violence, discrimination, and lack of information hinder TGD people in accessing sexual health services, prevention, and treatment. Throughout all interviews, these topics were recurring and dominated the discussions around the values and preferences for HIV, HCV, and STI services. Participants named several practical interventions that would improve access to HIV, HCV, and STI prevention, treatment and care and which should be considered in the update process of the values and preferences for HIV, HCV, and STI services.

9 He, J. et al., 2020, "Peer education for HIV prevention among high-risk groups: a systematic review and meta-analysis", BMC Infectious Diseases, (20) 388.

Needed interventions:

- Fight societal stigma and discrimination
- Improve access to legal gender recognition and gender-affirming care
- Offer education and training to healthcare providers, researchers, and policy makers about trans-specific needs and vulnerabilities
- Decrease the barriers to education and information about HIV, STIs, and viral hepatitis for TGD people
- Conduct more research and collect data about TGD experiences, needs, and vulnerabilities in order to produce adequate and scientifically sound prevention, care, and treatment materials to inform TGD communities
- Increase the inclusion of TGD people in research and data collection (not only as investigated populations, but also professionals in research design, implementation, data collection, and data dissemination)
- Increase the access to more funding for peer-lead services, initiatives and interventions
- Strengthen capacity building and professionalization options for TGD community members with regard to HIV/STI prevention and care
- Highlight the need for targeted prevention campaigns interventions must consider the diversity of TGD identities (i.e., including transfeminine, transmasculine, AND non-binary trans identities) and their diverse bodies
- Increase the inclusion of TGD people in all (decision making) boards, panels, group, advisory committees, taking into consideration the diversity of our community (i.e., including transfeminine, transmasculine, AND non-binary trans identities) that work on the risks and vulnerabilities of key populations

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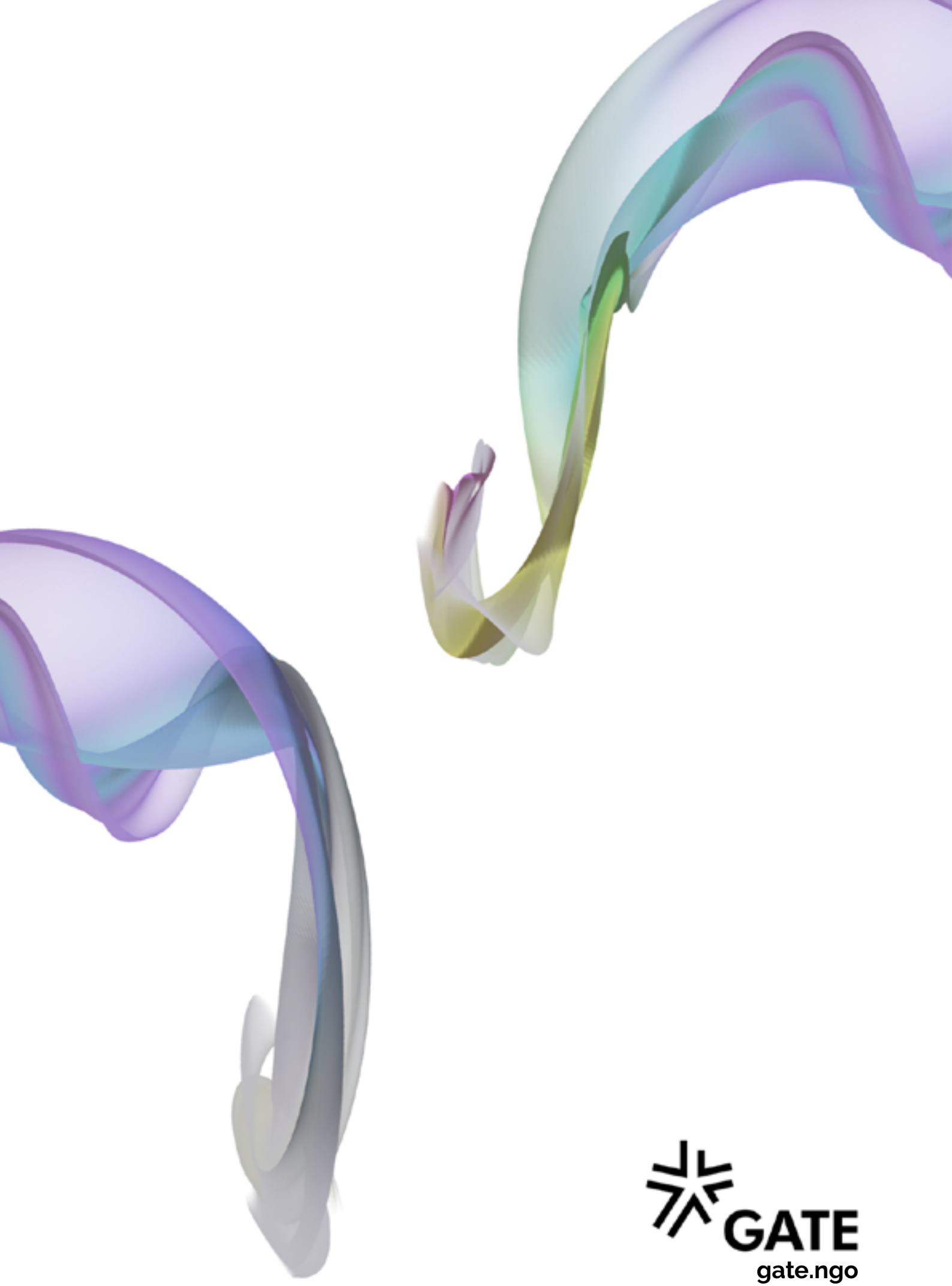

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