

Values and preferences of transgender people: a qualitative study

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2014

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Acknowledgements

We would like to thank the 14 individuals who agreed to be interviewed for their participation in this values and preference survey and for generously sharing their experiences and insights as transgender people.

We also gratefully acknowledge the contributions of the following experts who participated in the Delphi consultation process for this study:

Diana Abou Abbas (Marsa Sexual Health Center, Lebanon), **Stefan Baral** (Johns Hopkins Bloomberg School of Public Health, USA), **Anamaria Bejar** (International AIDS Alliance), **Azhar Bin Kasim** (Malaysian Aids Council), **Danielle Castro** (Center of Excellence for Transgender Health, University of California at San Francisco, USA), **Philip Castro** (United Nations Development Programme), **Cecilia Chung** (Global Network of People Living with HIV North America), **Vivek Divan** (United Nations Development Programme), **Justus Eisfeld** (Global Action for Trans* Equality), **Luis Gutierrez-Mock** (Center of Excellence for Transgender Health, University of California at San Francisco, USA), **Geoffrey Jobson** (Anova Health Institute, South Africa), **JoAnne Keatley** (Center of Excellence for Transgender Health, University of California at San Francisco, USA), **HeJin Kim** (Gender DynamiX, South Africa), **Ruben Mayorga** (Joint United Nations Programme on HIV/AIDS), **Rafael Mazin** (PanAmerican Health Organization/World Health Organization), **Midnight Poonkasetwattana** (Asia Pacific Coalition on Male Sexual Health, Thailand), **Tonia Poteat** (Office of the U.S. Global AIDS Coordinator), **Prempreeda Pramroj Na Ayuthaya** (United Nations Educational, Cultural and Scientific Organization, Bangkok), **Anita Radix** (Callen-Lorde Community Health Center, USA), **Magdalena Robinson** (Transgender COLORS, Inc., Philippines), **Alfonso Silva Santisteban** (Universidad Peruana Cayetano Heredia, Peru), **Khartini Slamah** (Asia Pacific Transgender Network), **Johnny Tohme** (Marsa Sexual Health Center, Lebanon), **Frits van Griensven** (Thai Red Cross AIDS Research Center), **Hege Wagan** (Joint United Nations Programme on HIV/AIDS), **Conrad Wenzel** (San Francisco Department of Public Health, USA) **Erin Wilson** (San Francisco Department of Public Health, USA).

We also thank the transgender organizations and networks and the individuals that helped disseminate the invitation to individuals to participate in the study:

African Sex Worker Alliance

Asia Pacific Coalition on Male Sexual Health (APCOM)

Asia Pacific Network of People Living with HIV/AIDS (APN+)

Asia Pacific Trans Network (APTn)

Coalition of Asia Pacific Regional Networks on HIV/AIDS (7 Sisters)

FHI 360 Cambodia

GenderDynamiX

Global Action for Trans* Equality (GATE)

Global Forum on MSM and HIV (MSMGF)

ILGA EUROPE: Equality for lesbian, gay, bisexual, trans and intersex people in Europe
India Network of Sexual Minorities
Naz Male Health Alliance
Oogachaga Counselling and Support (OC)
OUT Well-Being
Rainbow Identity Association (RIA)
Red de Personas Trans de Latinoamérica (REDLACTRANS)
Sampoorna: A Network of Trans Indians across the Globe
S.H.E, Social, Health And Empowerment Feminist Collective of Transgender and Intersex Women of Africa
TGEU – Transgender Europe
Totem Jeunes
Transgender and Intersex Africa (TIA)
TRANSGENDER Asia Research Centre
Transgender Network Switzerland
Ana Coimbra
Sam Winter

Abbreviations and acronyms

AFRO	WHO Regional Office for Africa
ART	antiretroviral therapy
EMRO	WHO Regional Office for the Eastern Mediterranean
EURO	WHO Regional Office for Europe
HIV	human immunodeficiency virus
HTC	HIV testing and counselling
LGBT	lesbian, gay, bisexual and transgender
MSM	men who have sex with men
NGO	nongovernmental organization
PAHO	Pan American Health Organization/WHO Regional Office for the Americas
PEP	post-exposure prophylaxis
PrEP	pre-exposure prophylaxis
SEARO	WHO WHO Regional Office for South-East Asia
STI	sexually transmitted infection
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development Programme
WHO	World Health Organization
WPRO	WHO Regional Office for the Western Pacific

Definitions of key terms

Transgender is an umbrella term for all people whose internal sense of their gender (their gender identity) is different from the biological sex they were assigned at birth. Transgender people choose different terms to describe themselves. Someone born female who identifies as male is a transgender man. He might use the term "transman", "Female to male (FtM)" or "F2M", or simply "male" to describe his identity. A transgender woman is someone born male who identifies as female. She might describe herself as a "transwoman" "Male to Female (MtF)", "M2F" or "female" (1).

Cis-gender is the opposite of transgender and refers to someone whose biological sex matches their gender identity (1).

Hetero-normative describes a world view that promotes heterosexuality as the normal or preferred sexual orientation.

Hormone therapy (also known as cross-gender hormone therapy or hormone replacement therapy) is a health intervention used by many transgender people. Hormones can be used to feminize or masculinize one's appearance in accord with one's gender identity. Physical appearance is often used to support assumptions about someone's sex, and hormone therapy can help a transgender person to be recognized as the appropriate gender (1).

Transition refers to the process transgender people undergo to live in their gender identity. This may involve changes to outward appearance, mannerisms or to the name someone uses in everyday interactions. Transitioning may also involve medical steps such as hormone therapy and surgery (known as **gender-affirming surgery**) (1).

Executive summary

The World Health Organization's (WHO) HIV Department has developed consolidated guidance on HIV among key populations, including transgender persons (2). As part of this process, a qualitative “values and preferences” study was conducted with transgender individuals from across world regions. The aim of these interviews was to ensure that transgender people's experiences with regard to HIV and broader health issues were captured and to foster better understanding of transgender-specific HIV and health issues. Specifically, the interviews sought to discover barriers and enablers as well as suggested strategies with regard to HIV information, prevention, testing, treatment, access to health services and other needs specific to transgender health.

To develop this values and preferences report, a three-stage process was employed. First, a desk scoping-review was carried out to gather available evidence about transgender people and HIV. Second, a two-round Delphi consultation was conducted via an electronic survey to invite experts in the field of transgender health to inform the design of the interview guide. Third, in-depth telephone interviews were carried out with 14 transgender individuals from across WHO regions.

Selective sampling was employed to identify a range of transgender men and women from different WHO regions and age groups, with differing HIV statuses and stages of transition. 14 transgender individuals (11 transgender women; 3 transgender men) took part in an in-depth interview. Respondents came from AFRO, WPRO, SEARO, PAHO and EURO regions; no transgender individuals from EMRO could be identified who would agree to take part in the interviews. The respondents' ages ranged from 22 years to 60 years. Three out of the 14 transgender individuals interviewed were living with HIV and three did not know their HIV status.

Respondents said that friends, the transgender community and the Internet were an important **source of information**, support and empowerment. However, many participants perceived the overall scarcity of transgender-specific health information – particularly on hormone treatment and gender-affirming surgery – as well as the trustworthiness of existing sources of information as a severe challenge. Overall, many of the respondents felt that more information on transgender-specific health concerns needs to be available and accessible, while existing HIV information needs to be tailored to address transgender people.

With regard to seeking **HIV testing and counselling (HTC)**, commonly mentioned barriers included hetero-normative environments that are not sensitive to transgender people; service-providers low levels of competency in transgender-specific issues; and transgender people's low levels of trust in service-providers. Fear of HIV, which was related to external and internalized stigma, was also a barrier to seeking HTC. These services should be rapid, free, confidential and transgender-friendly in order to increase the number of transgender individuals who seek testing. Staff should also be trained to give advice or make referrals to other transgender-specific health services, such as

hormone treatment. NGO-based testing, mobile clinics or community drop-in centres were also viewed as desirable modes of delivering HTC to the transgender community.

HIV prevention strategies were discussed, including sexual transmission, transmission through injections and the use of antiretroviral therapy (ART) to prevent transmission. While access to condoms was generally described as easy, other **prevention commodities** such as dental dams and lubricants were often unavailable. Despite the availability of condoms, low self-esteem, societal pressures and the fear of experiencing rejection from sexual partners were barriers to using them consistently.

The use of hormone **injections** appeared to vary widely between individuals and settings, with the majority of interviewees not considering the use of injections as a major HIV related concern. Injecting other substances such as silicone for gender-affirming body modification was reported as a major health concern in some settings.

Overall there was very little knowledge on **pre-exposure prophylaxis (PrEP) and post-exposure prophylaxis (PEP)** among the transgender individuals interviewed. Very little information on PrEP and PEP appeared to be circulating within the transgender community, and information that was available was targeted towards men who have sex with men (MSM) only. There were divergent opinions about whether PEP and PrEP should be promoted among the transgender community. Further research on the appropriateness and acceptability of PrEP and PEP among transgender individuals is suggested.

Three out of the fourteen individuals interviewed were living with HIV and taking **ART**. Among these individuals, stigma and discrimination from the health system and ART side-effects were described as challenging. HIV negative interviewees had concerns over possible interactions between ART and hormone therapy and the effectiveness of both treatments when taken together. Education and empowerment around ART, and the creation of treatment services in which transgender people feel comfortable and addressed in their transgender-specific HIV related concerns, were regarded as helpful for improving uptake and adherence to ART among those interviewed.

Transition-related concerns were found to be the major health priority among transgender individuals interviewed. The overall lack of transition-related information and services in the public health system, with regard to both hormone treatment and gender-affirming surgery, were seen as the greatest challenges to transgender people in achieving their highest attainable state of health. Transitioning was perceived as a vital pre-requisite for other physical and psychological aspects of health. Self-administered hormone use was widespread and reliance on non-medical guidance was common. Many individuals expressed concern over the potential adverse effects of non-supervised **hormone use** and wished to access non-discriminating, transgender-specific guidance through the health-care system. Similarly, those who desired to seek **gender-affirming surgery** also faced multiple

barriers through the health-care system, including lack of services, high costs, long waiting times, poor capacity and poor quality of services. Resulting psychological distress was commonly mentioned, with some individuals describing their depression and suicidal ideation as direct results of being unable to access gender-affirming treatments. In conclusion, providing competent and non-discriminatory transition related treatment and care services through the public-health system is considered vital for improving physical and psychological health among transgender people.

The results of this qualitative values and preferences survey, alongside technical reviews of existing evidence, has informed the development of the HIV consolidated guidelines for key populations as pertaining to transgender people. Furthermore, this report may also be used to inform interventions at multiple levels, including HIV research, programmes, policy and advocacy.

Introduction and background

Transgender people are disproportionately affected by a variety of physical and mental health risks. Stigma and discrimination, and a lack of prevention, treatment and care tailored for transgender people combine to exacerbate health risks. Transgender-specific health needs are often severely neglected in policy, research and service provision across the globe.

A high burden of HIV is one of the major health disparities facing transgender people worldwide. Numerous social, economic and individual factors combine to heighten transgender people's risks of acquiring HIV and thus make them a key population in need of HIV prevention, treatment and surveillance. A recent global meta-analysis of HIV prevalence among transgender women documented 19.1% HIV prevalence among 11 066 transgender women across 15 countries, with the odds ratio of HIV infection among transgender women compared to the general population being 48.8 (3). A meta-analysis conducted in 2008 among US-based transgender women reported 27.7% HIV prevalence, with 73% of transgender women being unaware of their HIV status (4). A global systematic review on sex work and HIV revealed 27.3% HIV prevalence among transgender women who were engaged in sex work (5). While these studies document a high burden of HIV, predominantly among transgender women in the United States, quality data on HIV prevalence among transgender men and women from other regions, as well as studies estimating the size of the global transgender population, are urgently needed.

Despite their HIV related needs and risks, transgender people continue to be neglected and underrepresented among key populations (6, 7). Transgender community groups have voiced growing concerns over the discrepancy between their health needs and the funding, research and programmes allocated towards them, and have urged United Nations agencies to systematically address these gaps (8). With HIV among the leading health issues facing transgender people, WHO has been working regionally to address HIV and some of the broader health concerns facing transgender populations (9, 10, 11, 12). There is an urgent need to further address the HIV related needs of transgender people worldwide, as well as the underlying structural, social, individual and biomedical factors underpinning the HIV epidemic among this key population.

The WHO's HIV Department has consolidated normative HIV guidance for key populations, including transgender people (2). As part of this process, a background-scoping exercise on the current global state of evidence around transgender people and HIV was conducted. Next, experts in the field of transgender health and HIV were consulted in order to identify gaps in existing knowledge around HIV and transgender health. Finally, a values and preferences survey, in the form of qualitative interviews with transgender people, was conducted to ensure that the voices of transgender men and women were considered in the guideline process. Specifically, the interviews attempted to capture the experiences, needs, values and preferences of transgender people with regards to HIV prevention, treatment and care.

This report summarizes the findings of the qualitative interviews conducted among transgender people from across WHO world regions. The results of this qualitative survey, alongside technical reviews of existing evidence, have informed the development of the sections of the HIV consolidated guidelines relevant to transgender people.

Methods

Prior to conducting the values and preferences interviews, a desk scoping-review on HIV and other health-related needs among transgender people was completed. The scoping exercise gave an overview of HIV related epidemiology, prevalence, risk factors and access to health services among transgender people globally. It also provided an overview of existing WHO guidelines and recommendations with special considerations for transgender people and HIV. Research gaps and recommended ways forward for WHO were highlighted. The document concluded that conducting values and preferences interviews with a sample of transgender men and women from across world regions should be a priority action for WHO in light of the development of the 2014 key populations consolidated HIV guidelines.

The Delphi process

In preparation for the values and preferences interviews, an online Delphi consultation was conducted with a group of experts in the field of transgender health and HIV, to gain consensus on the most important topics for inclusion in the in-depth interviews. The Delphi method is a structured process for collecting and distilling knowledge from a group of experts using a series of questionnaires, which are then summarized for further opportunities for controlled feedback of opinions. The Delphi consultation was conducted in two rounds via an electronic survey using *Survey Monkey*. Summarized responses from Round 1 were returned to participants, along with the Round 2 questionnaire, which excluded those questions on which consensus had already been reached.

Round 1 Delphi

WHO Regional offices were informed of the Delphi consultation and asked to provide contacts to key regional experts in transgender health and HIV to be included in the Delphi exercise. Using these contacts, together with well-known experts from academia and international organizations, a total of 44 individuals were invited via e-mail to participate in the Delphi exercise. A week following the initial invitation, the link to the Round 1, 27-item survey questionnaire (see Annex 1) was sent out and the survey was kept open for one week, with one reminder e-mail sent out one day prior to survey closure. Round 1 was completed by 24 experts (a 54.4% response rate). Respondents were anonymous to one another, and only the research team was able to access details of those participating. Responses to each question were summarized using descriptive statistics.

Round 2 Delphi

Based on Round 1 analysis, the Round 2 survey was developed, including a summary of all items on which there was consensus (which was predetermined as being 51% agreement by respondents on any given question (13)). All items with less than 51% agreement, as well as any novel

topics raised in Round 1, were included in this second questionnaire for the purpose of ranking.

The 24 experts who had participated in Round 1 were sent an e-mail summary of Round 1 results and the link to access the Round 2 survey. The survey link was kept active for one week, with one reminder e-mail sent one day before closure. Eighteen experts participated in Round 2 (a 75% response rate among those who had participated in Round 1). Following analysis, participants were again informed of the results of Round 2.

The in-depth interviews

Transgender participants who took part in the values and preferences interviews were recruited using a convenience, snowball sampling method. Experts who had been contacted through the Delphi process were asked to provide contact details of transgender individuals from their networks or Region to partake in the in-depth interviews. Based on the contacts provided, 72 transgender individuals were identified and personally invited via e-mail to take part in the interviews. Further recruitment of transgender individuals was done via advertisements circulated through social media websites, organizational networks and mailing lists. Thirty-five transgender networks and organizations, representing all major regional transgender networks and NGOs as well as key local networks, were contacted via e-mail and asked to forward an invitation to their transgender members.

The recruitment letter (see Annex 2) included a link to a short *Survey Monkey* online survey (see Annex 3), in which transgender individuals were asked to register their interest in taking part in an in-depth interview by providing basic sociodemographic information. The short online survey was completed by 34 transgender individuals. In an attempt to achieve equal regional representation and capture a wide range of varying persons with regard to age, gender, transition stage and HIV status, 19 transgender individuals were invited to take part in an interview. Fourteen individuals agreed to be interviewed and interviews were arranged on an individual basis.

Interviews were conducted in December 2013 and January 2014 by an independent consultant, via telephone or Skype. A semi-structured interview guide which was developed based on the results of the Delphi consultation and scoping review was used to guide interviews (see Annex 4). Topics covered in the interviews included HIV knowledge, prevention, testing and counselling, treatment and care, antiretrovirals as prevention and other health concerns. Open-ended questions were used to encourage in-depth expression of personal experiences, opinions and perspectives by interviewees.

At the start of each interview, the interviewer verbally reviewed the participant information sheet which the participant had been sent prior to the interview, before taking verbal consent (see Annex 5). Interviews took 50–90 minutes to complete. All interviews were conducted in English, with the exception of one, which was conducted in Spanish, using a Spanish–English translator arranged by the interviewee.

All interviews were recorded and then transcribed verbatim by the consultant. Information provided during the interview as well as the short online survey was anonymized so that only the consultant was able to access personal details of interview participants.

Transcribed interviews were entered into the qualitative analysis software *QDA Miner Lite*. Each interview was then re-read and coded thematically using the software. Coding was organized into topics covered on the interview guide, while novel themes and topics emerging out of the data were also included. Content for each code or theme was then retrieved separately and all quotations pertaining to one theme or code were re-read and analysed for content. The narrative section on each theme was then written.

Respondent demographic and psychosocial profiles

Tables 1–3 provide an overview of the basic demographic information of the 14 transgender individuals interviewed. Eleven transgender womenⁱ and three transgender menⁱⁱ were included in the interviews. Respondents came from Brazil, El Salvador, Fiji, France, India, Indonesia, Philippines, the Russian Federation, Singapore, South Africa, Thailand and the United States, representing five different WHO Regions. (For the Eastern Mediterranean region no transgender individuals could be identified who would agree to take part in the interview.) Respondents' ages ranged from 22 years to 60 years. All except one participant were working with transgender or health-related organizations. Three out of the 14 transgender individuals interviewed were living with HIV and taking ART. Eight respondents reported being HIV negative, while three did not know their HIV status. Of these three, two reported never testing for HIV in the past.

Table 1. Respondent profile by gender and region of residence

	AFRO	WPRO	SEARO	PAHO	EURO	EMRO
Transgender woman	2	2	3	3	1	-
Transgender man	-	1	-	1	1	-
Total	2	3	3	4	2	-

Table 2. Respondent profile by gender and age

	19-29	30-39	40-49	50-60
Transgender woman	4	4	2	1
Transgender man	1	2	-	-
Total	5	6	2	1

Table 3. Respondent profile by HIV status

	HIV +	HIV -	HIV status unknown
Transgender woman	3	5	3
Transgender man	-	3	-
Total	3	8	3

ⁱ Transgender women are people whose current gender identity is female or transgender female but who were assigned male sex at birth.

ⁱⁱ Transgender men are people whose current gender identity is male or transgender male but who were assigned female sex at birth.

Key Findings

Topic 1: HIV and transgender health-related information: access and sources

SUMMARY BOX: HIV and health-related information

Supportive factors and enablers:

- Sources of information relating to HIV and transgender health that were identified by interviewees were: friends and the transgender community; the Internet and social media; transgender and HIV organizations; UN agencies; national governments and research and academia.
- Friends and the transgender community appear to play a vital role in creating, distributing, validating and endorsing information on HIV and transgender health-related issues.
- Information was commonly sought out and shared on the Internet and social media sites.
- Information was sought both from within the transgender community and outside: the transgender community itself served as an important resource in creating and sharing information and knowledge with regards to transgender health, while individuals working in transgender health-related organizations also turned to governments, UN agencies and academia to look for validated information which could then be adapted to the local context.

Challenging factors and barriers:

- A lack of transgender-specific information and research was seen as the greatest barrier to accessing information on HIV and other health issues.
- Many transgender individuals perceived themselves as being a minority within the lesbian, gay, bisexual and transgender (LGBT) community, and conflation of their issues with those of men who have sex with men issues in particular was perceived negatively.
- Information specific to transgender people and research into hormone use and its potential impacts and interactions on HIV prevention, risks and treatment was also widely said to be lacking.
- The trustworthiness and language barriers associated with available transgender-specific information sourced from the Internet was raised as a concern by a few participants.

Suggested solutions:

- Information on HIV and other health-related information should be made specific to transgender men and transgender women, and they should not be addressed as a sub-population within LGBT or heterosexual HIV frameworks.
- Transgender-specific health information should be available in ways that do not exclude transgender people who are illiterate, non-English speaking and non-Internet users.
- More research should be done on transgender-specific health issues, such as potential interactions between gender-affirming treatment and ART treatment.

Supportive factors and enablers

Nearly all individuals interviewed reported friends and the transgender community as the prime source of HIV and other health-related information, peer support and a strong sense of community. Exchange of information occurred both through face-to-face and virtual connections with other transgender individuals. Across respondents, friends and the transgender community were portrayed as a vital source of information, support and empowerment.

"We take care of each other and that goes a huge long way towards helping ameliorate the difficulties that we're facing in trying to get information... we're not just lonely, single people out in the cold waiting for the door to open and for us to be brought in. We have amazing communities already, we take care of each other... and I would say, that's one of the best things about being trans."

Transgender man, 31, United States

A majority of interviewees mentioned the importance of the Internet and social media in providing health-related information, included social network sites and transgender-specific blogs.

Many reported actively searching the Internet for information on hormone use, gender-affirming surgery and health-care services and service-providers, as well as to connect to peers. Using the Internet to access HIV specific information was mentioned less frequently.

"When I started my hormone therapy, I started going into Facebook groups and checking information on what they are taking ... I also could find some online resources from some Canadian reports on hormone therapy and other transition methods."

Transgender woman, 29, Brazil

"Some older transgenders shared their experience of using the hormones and other things... I read a lot of Internet because I cannot get any access from the medical practice, medical providers..."

Transgender woman, 22, Indonesia

Responses also suggested that the majority of information consulted on the Internet by transgender people largely came from the transgender community itself or was in some way endorsed by the transgender community, and hence was considered more trustworthy. Furthermore, numerous responses suggested that the high reliance on information from peers and the Internet was due to a lack of information elsewhere, such as through the medical system or research.

"If I'm on Facebook or if I'm on Tumbler and I see WHO recommending that this is a set of recommendations and this is what you should do, this is what you should not do... I won't share that, I won't tweet that. But if it's coming from someone who is prominent in his region or her region, or someone who is a known figure somewhere, who is part of the community, and then I will say, "Oh yes hey, if she is endorsing it or he is endorsing it, there must be some truth in it."

Transgender man, 29, Singapore

All except one interviewee worked in transgender- or health-related organizations, reporting these as important sources of information on HIV and broader health issues. This is likely to have had a strong bearing on the level of

information available to the transgender individuals interviewed here. Some of these individuals explicitly mentioned directly seeking out information related to HIV and transgender health from publications from government, UN agencies and academic research and then contextualizing such information to fit their local needs.

"Our main source of information is coming from the UNO, the manuals that United Nations gave us and still continues to give us."

Transgender woman, 35, El Salvador

"In terms of latest technologies, latest medications, even interventions, things of that nature, we normally get it through our funders."

Transgender woman, 44, United States

Challenging factors and barriers

A lack of transgender-specific information overall was perceived by the majority of transgender people interviewed as the major barrier to accessing HIV and transgender-health related information. Among individuals not self-identifying as men who have sex with men, several perceived the conflation of transgender issues with other LGB issues – and in particular with MSM issues – as frustrating. Though a less common experience, some individuals also said that the discourse on HIV in their context was predominantly targeted at heterosexuals. This was seen as preventing transgender-specific issues from being adequately addressed.

"The sad thing is that trans women are lumped within those MSM approaches, within those MSM statistics, within those MSM interventions. Transwomen are not MSM. Once you start focusing on MSM and you include transwomen, you have already missed us."

Transgender woman, 31, South Africa

The main gaps in information identified by transgender individuals pertained to gender-affirming surgery and hormone use, including concerns about potential interactions with ARTs and HIV test results. Furthermore, a lack of transgender-specific information on HIV prevention and effective interventions was identified as a major gap.

"I did not know whether hormones have any interference with the test results and I can't find anything on that at all... it was just hard because there are times whereby my results came back inconclusive, so I get positive results, I get negative results, during my screening test... And I also don't know how effective treatment is when one is on hormones."

Transgender man, 29, Singapore

Some participants reported that efforts were being made to target HIV messaging towards transgender populations, but they still felt frustrated by these efforts. Others raised concerns about the complete absence of

transgender-specific HIV awareness information in their countries, feeling that their needs for information were not being addressed.

“Even if UN agencies – UNAIDS or UNFPA or all these UN agencies or regional agencies talking about HIV – [are] making sure that we also prioritize key populations, it’s still not reflected in terms of awareness messaging and packaging. There is still no specific awareness information available, or material that’s specific to our needs. So I don’t think that it’s fully addressed... They can have their conversation in their offices, but its not reflected in the information that is going around in the community. There are no television, newspaper or printed materials on the specific needs of transwomen and transmen and how they can protect themselves from HIV. It’s still the old same heterosexual packaging.”

Transgender woman, 28, Fiji

The uncertain reliability and trustworthiness of available information on transitioning, particularly on the Internet, was described as a frustration and concern by several individuals.

“It is very frustrating, the information is out there but you don’t know which one you can trust... Using social media, I think it’s a good platform but we need to know how to really seek out this information and whether it is true or it is not.”

Transgender man, 29, Singapore

A few participants said that language barriers to transgender-specific information available on the Internet present a challenge to illiterate or non-English speaking transgender people. Limited access to the Internet was also a barrier to accessing relevant information for some.

“I haven’t found any website or information written in Thai about hormones for transgender. I found some article in English. But it’s lucky for me that I can read, I can write English. But for the [other] people, especially for the transgender in Thailand, it’s just very difficult for them... to understand the scientific term, the vocabulary and the term they use.”

Transgender woman, 29, Thailand

Suggested strategies for improving access to HIV information

Many transgender individuals suggested that addressing transgender health needs separately from the needs of LGB populations was an important step towards providing access to HIV and other health information for transgender people. Two participants suggested that information on HIV and health should be made specific to transgender women and transgender men, to ensure that their specific needs are met. Furthermore, some participants urged that transgender-specific health information be accessible to illiterate, non-English speaking and non-Internet using transgender people, by making it available in local languages and in nonverbal forms, such as by using the creative arts.

“And one other thing that needs to be highlighted is that transgender people are transgender men and transgender women. When we work on key affected populations we call them MSM, we call them women and girls, but then when it comes to transgender, it's “transgender”. But there are actually two genders in transgender: there are men, there are women.”

Transgender man, 29, Singapore

Topic 2: HIV testing and counselling (HTC)

SUMMARY BOX: HIV testing and counselling

Challenging factors and barriers:

- Hetero-normative, judgemental and non-transgender sensitive services were perceived as the greatest barrier to seeking HTC among many individuals interviewed.
- The fear of getting a positive result also prevented some from seeking testing.
- Some individuals mentioned concerns over confidentiality, long waiting times at testing facilities, having to travel long distance to a testing facility, a lack of follow-up or referrals and the cost of testing as further challenges.
- The importance of receiving counselling and support after testing and the absence of this during self-testing was highlighted by some individuals.

Supportive factors and enablers:

- For many individuals, the importance of knowing one's HIV status was the primary motivating factor for seeking HIV testing.
- Encouragement from peers and access to fast or free testing – including free rapid testing – were factors that encouraged several individuals to get tested.
- Confidential and transgender-sensitive testing services were seen as vital enablers for wanting to get tested.

Suggested strategies:

- HIV testing should be confidential, free and rapid where possible.
- Testing services should be transgender-sensitive and non-judgemental.
- Staff and counsellors should be trained and sensitized on transgender health issues in order to be able to deliver transgender-specific HTC.
- Staff should also be trained to give advice on or make referrals regarding important transgender health issues, including hormone treatment.
- NGO-based testing, mobile clinics or community drop-in centres were viewed as desirable modes of delivering HTC to transgender communities.

Challenging factors and barriers

Among those who had been tested for HIV, a majority perceived the hetero-normative and non-transgender sensitive testing environment to be a major problem. Respondents commonly felt stigmatized, discriminated against, unwelcome and misunderstood, making it difficult to raise their concerns. Subsequently, some respondents strictly avoided such testing environments.

“The problem is that if you get tested... the people who provide testing think very much hetero-normative, heterosexually... which makes it very hard for a trans person to sort of raise your issues to them. So it's not a sort of a place where I would go unless it's absolutely, absolutely necessary, and I can imagine – and I know this from being in the community – that a lot of people refuse to go for that reason.”

Transgender woman, 30, South Africa

Some transgender people reported being perceived as cis-gendered people when they went for HTC. Thus they perceived the risk assessment to be of little help, or even annoying.

"The testing itself was very [hetero-]normative, because the person who tested me first of all read me as a cis-gender woman and the questions that he asked in the risk assessment was the questions that would be applicable for a cis-gender woman with a vagina... the risk analysis was not proper and it was based on an assumption and on some misconceptions."

Transgender woman, 31, South Africa

Overall, a low level of trust in service providers at testing centres was expressed. Many transgender individuals felt they had to educate the health-care staff to be more knowledgeable on transgender-related HIV issues and more sensitive towards transgender clients. This was described as an "overwhelming explanation" and an uncomfortable experience overall. A few interviewees also reported experiencing similar barriers at settings which they felt should have been less hetero-normative, such as at LGBT clinics and international conferences.

"I don't want to have to go to test somewhere every time where I feel I have to educate the nurse on my risk and my risk behaviour."

Transgender woman, 31, South Africa

"...if you are working in an LGBT clinic you have a responsibility to recognize that there are trans people there, we are not the hugest population, but we're there and we might not look like what you think... and it's not my responsibility to do your job for you."

Transgender man, 31, United States

Some individuals also felt reluctant to getting tested because of their fear of testing positive. They described feeling nervous, scared or emotional prior to taking their test and "not ready to deal with whatever is going to be said", describing HIV as a "scary disease". Aside from these fears, reactions from society and the possibility of not being allowed gender-reassignment surgery were perceived as risks associated with a positive HIV test.

"It takes a lot psychologically to get up in the morning, to sit in those long lines, to test... When I went for testing the other day ... I went into the counselling room, I was counselled, I left without testing because I wasn't sure whether I am ready to deal with whatever is going to be said there."

Transgender woman, 31, South Africa

"How do you live and how do you deal with the reaction from the society when you got the result, especially when it is positive? People are afraid to get an HIV test ... they have no idea what to do if they have the positive result... Some people believe that if

you have HIV, it means you're going to die soon... And yes, when it comes to the workplace... people living with HIV are not accepted."

Transgender woman, 29, Thailand

Some participants voiced concerns over the confidentiality of getting an HIV test. A few participants also identified the long distance to a testing facility, long waiting time at the facility, and the direct and indirect costs associated with HIV testing as further barriers to getting tested.

"Transgender women, for example if they live in a specific zone where they have health care there, they don't go to that clinic, but they go very far away from their home to take the test ... because for example there are neighbours or friends or somebody who knows them and who might make public their result."

Transgender woman, 35, El Salvador

A lack of follow-up on HIV test results and referral to other services in the case of a positive test result were mentioned by a few participants as barriers to retaining transgender individuals in HIV care.

"The reason why I didn't go back for my results was that there was no follow-up... I was actually expecting them to follow up on all of the people that were testing. But no one called me for my results."

Transgender woman, 28, Fiji

Two participants reported never having been tested for HIV. They expressed no real need to get tested, primarily due to a low self-perceived level of HIV risk.

"It didn't come to my mind that I have to go for the HIV test or that I don't have to go. ... since I am not into that much of unsafe sexual practice, I don't get tested at the moment."

Transgender woman, 40, India

A few participants spoke about the possibility of self-testing, raising concerns about the lack of professional support and counselling in such circumstances.

"I think that is a bit of a risk because you don't know how people are going to be able to handle their status. I for example would not want to self-test. I do think there is value in a trained person like a counsellor coming to test you... Because if you self-test, you don't always know all the facts... So if I am positive and I have tested myself, who will be able to answer those questions for me?"

Transgender woman, 31, South Africa

Supportive factors and enablers

When asked what motivated individuals to seek testing for HIV, interviewees generally expressed a desire to know their own status. Having access to easy, fast and free testing which is at the same time confidential and transgender-friendly was seen as an important prerequisite for getting tested. Rapid testing was viewed as desirable, due to the fact that results could be obtained quickly. Providing testing that is explicitly targeted towards transgender people or which involves transgender peers at the testing facility also encouraged individuals to get tested.

“My guy friend told me that there is a free test and the results will come out after an hour... I really want to try it. Because it's easy, it's fast and it's free... to know your status is much better than you don't know anything about your status.”

Transgender woman, 22, Indonesia

“What motivated me to join this test was because it was targeting a specific group – it was targeting our group.”

Transgender woman, 28, Fiji

Suggested strategies for improving HIV testing and counselling

The majority of transgender individuals interviewed agreed that having access to confidential testing was essential to improve the HIV testing experience. Some additionally mentioned the necessity of having access to free testing. The view that HIV testing facilities should become transgender-inclusive, transgender-sensitive and non-judgemental was pervasive across respondents. Specifically, interviewees felt that testing services should be “welcoming”, “friendly” and offer “positive advice” to transgender clients, in order to make them feel more comfortable. Many felt that training and sensitizing staff on transgender-related health needs and risks could help achieve this and challenge the current hetero-normative approach of testing and counselling. Several individuals expressed the view that staff should be trained to offer advice – or at least be able to make a referral – on other important transgender-related health issues, such as hormone treatment, gender-affirming surgery and mental-health services.

“[HTC providers] need to make sure that there is confidentiality. There is a lot of confidentiality issues... and these need to be resolved in order for people to start wanting to get tested... It's also about education: people who provide the testing should be taught about trans-specific issues in terms of HIV, they should be taught to provide transgender-friendly services.”

Transgender woman, 30, South Africa

“Because we live in a community that's so small... I would want to go to a hospital where no one would totally know me or see me entering. Most of the facilities and the locations of the clinics where testing is currently underway... are very visible to the public... So if I were to go to for testing again, it would have to be somewhere very secluded, or maybe a mobile clinic, that would come at night and do testing for key populations...”

Transgender woman, 28, Fiji

Some interviewees also suggested that offering testing through transgender-based organizations such as NGOs in the form of community drop-in centres or mobile clinics would be a successful strategy for increasing the uptake of HTC among transgender people.

"I don't really like going to hospitals and things like that. I would like to suggest that if there was something to motivate me to go for testing, it would be like a drop-in community centre for trans women that offers different kinds of services, as well as testing. That would be a really good initiative to actually get a lot of key populations to come for testing..."

Transgender woman, 28, Fiji

Topic 3: HIV prevention: access and barriers

SUMMARY BOX: HIV prevention: access and barriers

Prevention of sexual transmission:

- With the exception of prison settings, where lack of condom availability was described as a major challenge, the large majority of transgender individuals perceived condom access as easy and presenting few barriers.
- Difficulty in accessing other prevention commodities such as dental dams and lubricants, and the lack of transgender-specific marketing of prevention commodities, were raised as challenging factors.
- Low self-esteem, societal pressures and fear of rejection by sexual partners were seen as major barriers to consistent condom use by some interviewees.
- Traditional and medical circumcision as an HIV prevention measure for transgender women should be regarded with caution, as transgender women may feel violated by such "male-oriented" practices.

Prevention of sexual transmission through injections:

- Risk perceptions of HIV transmission associated with injections of hormones, silicone and other gender-enhancing substances varied widely among interviewees and settings.
- Injections by health-care staff as well as unsafe injections were reported, with the latter being more common for the illegal injection of gender-enhancing substances such as silicone.
- Access to clean needles was generally described as easy in most settings, but needle exchange programmes serving transgender people were not available.

Antiretrovirals for prevention: PrEP and PEP:

- Less than half of the transgender individuals interviewed had heard of PrEP or PEP.
- Available information came mostly through HIV related research or work, predominantly targeted towards men who have sex with men or sex workers, while awareness within the transgender community at large was assumed to be very low.
- The major barrier identified with regard to PEP and PrEP was the lack of transgender-targeted information.
- Further barriers that were mentioned included the cost of such treatments, a lack of access through the health system, potential side-effects, interactions with hormones and being on chronic medication.
- The few participants who were aware of PEP and PrEP expressed mixed feelings as to whether they should be offered or promoted within the transgender community.
- Overall, these findings suggest the need for more research on PrEP and PEP with regard to its appropriateness and acceptability among transgender individuals.

Prevention of sexual transmission

With the exception of prison settings, access to condoms, either commercially or through NGO programmes, was said to be easy by the large majority of interviewees. However, access to other prevention commodities such as dental dams and lubricants was described as more difficult, with supplies often unreliable.

Despite the availability of condoms, several individuals reported not using condoms with their sexual partner consistently. Some transgender individuals saw low self-esteem, societal pressures and fear of experiencing rejection from sexual partners for wanting to use a condom as barriers to practicing safe sex. The value of practising safe sex was sometimes perceived as secondary to the desire to avoid feelings of rejection and social isolation. Within sex work, clients' objection to using condoms was also described as a barrier to consistent condom use. Furthermore, one transgender man raised concerns over the marketing of prevention commodities for transgender men, suggesting that current marketing did not specifically address them.

“The fact that someone wants to have sex with us would mean that he doesn't mind my genitals, he doesn't mind my body, he doesn't mind anything about me – and do I [therefore] have the right to ask for safer sex? I mean, I might just turn him away and he would just brush me off like every other rejection that I have gotten like that living as a [transgender] person... It's more about wanting a kind of belonging and not wanting to be rejected again. Especially in that moment of passion, you really hate to be rejected. And once [sex without a condom] happens, it's something that keeps happening. You just keep thinking that this is normal, it's safe, you have not gotten [HIV] and it's safe to continue like that, because this must be the way to go to not get rejected.”

Transgender man, 29, Singapore

“There is a lot of information out there about how gay men have sex. And a lot of that I think makes it difficult for trans men, particularly those who are just newly transitioning and newly wondering about... what kind of sex they need to have, how much agency they have to control the circumstances under which it happens, and as a result what kinds of situations they put themselves in with regard to HIV or other kinds of STIs... You just pile onto all of this the hard time growing up, the hard time getting into relationships, the hard time transitioning, the hard time trying to feel like you are a normal functioning member of whatever social group you are in. If that were easier, then maybe we would have a little bit more energy for things like taking care of ourselves... And that all factors into... the decisions I was making around [questions like,] Is my life really worth it or do I want more to try to belong just for this little moment and forget about the consequences?”

Transgender man, 31, United States

A few interviewees cautioned that circumcision for prevention of sexual transmission was a potentially challenging HIV prevention strategy with regards to transgender women. Circumcision of transgender women was seen as a violation of bodily autonomy and female gender identity and one interviewee explicitly advised against inclusion of transgender women in circumcision practice.

“Many trans women feel that that circumcision is a violation of their gender identity because the circumcision itself goes beyond the snipping of the foreskin... it means society then sees them as men, which is the very notion that trans women reject. And our government is also encouraging medical male circumcision as an HIV prevention strategy. That is problematic because it looks at it from a “one size fits all” kind of approach.”

Transgender woman, 31, South Africa

Prevention of transmission through injections

Most of the transgender individuals were uncertain of the prevalence and frequency of hormone injections within their respective transgender communities. Nonetheless, the large majority of interviewees did not personally perceive the use of hormone injections as a major HIV related concern.

The reported mode of administering hormone injections varied by setting, with some participants reporting self-administration of hormones to be a common practice, while others said that hormone injections were administered by health-care staff and were thus perceived as safe. Yet in other settings, only oral hormone use was reported.

“Some girls who are travelling for leisure or business will buy a horde of injectable hormones from Thailand, for example, and they would bring it over to the Philippines and then they would have an injection party... and the nurse will inject them. So it's... a very clean procedure and its quite safe.”

Transgender woman, 36, Philippines

Some interviewees saw injections of soft tissue fillers such as silicone as a noteworthy problem within the transgender community. Mostly, silicone use was said to occur within lower-income groups and within transgender individuals working in the sex industry. One transgender woman reported that she had experienced numerous health problems as a consequence of receiving these injections. Most other participants were concerned by and hence avoided silicone injections, yet acknowledged that the comparatively low price of illegal injections was an incentive to use them. One participant further mentioned the injection of recreational drugs, in an attempt to cope with depression and social discrimination, as an additional HIV related risk factor within the transgender community.

“Beauty salons... provide silicone injection for their nose, their breasts, their hips...Those who [perform the injections] are not professional nurses or doctors. They just get it from the black

market ... Especially [those transgender people] who have occupation as prostitutes, they use that to enhance their beauty, their sex appeal... Illegal injections using silicone oil are quite prevalent here... because of the general poverty of trans people in my country, because they cannot afford gender-affirming surgery in either public or private [sectors], they... opt to get illegal injections from quacks."

Transgender woman, 22, Indonesia

Access to clean needles was generally said to be easy. Most transgender individuals mentioned being able to buy clean needles through a local pharmacy. None of the interviewees mentioned needle exchange programmes serving transgender people. A few participants recognized the cost of buying clean needles as a barrier to their use.

"I think in some ways part of the problem is that they [the state government] don't think about our community a lot. Needles for the most part are for people who inject drugs... there is probably one place that does provide thicker-gauge needles that are hormone needles here... Our community not only injects hormones but they also inject other physical enhancers."

Transgender woman, 44, United States

Antiretrovirals for prevention: PEP and PrEP

Overall knowledge on PrEP and PEP was low, with less than half of those interviewed having heard of either. Most knowledge on the subject appeared to come from professional contexts, i.e. among respondents working in health care or HIV related areas. There was general consensus that knowledge on PrEP and PEP was very scarce within the transgender community at large. Information on PrEP appeared to be even less available than information on PEP, with the latter being mostly spread through sex worker networks.

One transgender woman mentioned that information on PrEP and PEP sometimes became available in the community through research studies, and criticized the fact that such studies generally targeted men who have sex with men and were thus not widely accepted within the transgender women community.

"Unfortunately, in our community there is not a lot of knowledge about PrEP or PEP... There have been studies that have targeted MSM and they still include us in that and obviously we don't consider ourselves men, so because of that, people obviously don't participate... there has not been something that is specifically targeted to us, in regards to PEP and PrEP. And I guess once they do that, it's going to be something specific and obviously I am thinking the community is going to be welcoming... Even if at least they hire a trans person to recruit other trans women that would definitely make a difference, because in some ways you can convince people to participate."

Transgender woman, 44, United States

Apart from the general lack of information on PEP and PrEP in the transgender community, the high cost of these treatments, lack of access through the health system, potential side-effects, interactions with hormone treatments and a general aversion to taking yet another chronic medication (in the case of PrEP) were raised as further barriers to access. A few participants said that they did not consider PrEP or PEP to be relevant prevention options for themselves, explaining that they exclusively practised safe, low-risk sex and thus did not see the need for such treatments.

“Especially the trans sex workers, they know that if they have been raped, they need to access PEP, but for many reasons, some of them do not access PEP, because of issues within the health system. There are issues of discrimination and issues of prejudice... because if you are transgender, you often get denied this treatment.”

Transgender woman, 30, South Africa

“I would want a nurse to ask me if I go for PEP for example whether I am on any other medication, whether I am on hormones, because we don't know whether those hormone drugs might interact with post-exposure prophylaxis. So that is certainly a consideration for me and something that I think about very often.”

Transgender woman, 31, South Africa

Opinions and feelings on whether PEP and PrEP should be promoted among the transgender community were mixed. In general feelings towards PEP were more positive, while some expressed reservations about promoting PrEP. However, most participants said they had no or very little knowledge on the use of PrEP and PEP and thus few felt certain about whether they would make use of these treatments or about the acceptability of such strategies within their transgender communities.

“PrEP and PEP, especially for those gay trans men who are in a serodiscordant relationship, I think this information should be made available; at least we know that there are other preventive choices when it comes to sex, it's not just about condoms.”

Transgender man, 29, Singapore

“Yes, it [PEP] is wonderful. It should be written everywhere that it exists.”

Transgender woman, 60, France

“For me personally it's appropriate to focus on using condoms... How do we create circumstance in people's lives where they feel like they don't need to be in dangerous situations around sex? And if people are totally fine, they have good jobs, they feel like they have everything that they need and [then] they still have the kind of sex where they feel like they would want to be on PrEP: great.”

Transgender man, 31, United States

Topic 4: Antiretroviral therapy (ART)

SUMMARY BOX: ART

Challenging factors and barriers:

- Discrimination and stigma in the health system can result in outright refusal of treatment by health-care providers or actions that otherwise deter transgender individuals from seeking treatment.
- Stigma associated with ART may prevent transgender individuals from wanting to access it.
- Side-effects of ART were perceived as a challenge for gender expression, with one individual describing being unable to take hormone treatment while on ART due to adverse side-effects.
- The lack of access to treatment in prisons was raised as a major challenge for transgender people in prison.
- There were widespread concerns about harmful interactions between ART and hormone therapy.
- Many individuals criticized the general lack of guidance from the health-care profession to address these concerns.

Supportive factors and enablers:

- Education and empowerment of transgender people around accessing ART are an essential step to encourage transgender people to seek treatment.
- Adherence to treatment is supported if treatment services make transgender individuals feel supported, comfortable and that their specific needs are addressed.

Suggested strategies:

- Offering non-discriminatory and inclusive ART services, in which transgender individuals' specific concerns and questions relating to possible risks of ART and hormone use are addressed, may help to improve uptake and ART adherence.

Challenging factors and barriers

Three of the 14 interviewees reported that they were living with HIV and taking ART. One HIV positive transgender woman described an instance of discrimination from her doctor, where she had been refused treatment. Another transgender woman described the side-effects of her ART as a major challenge to her gender expression. Having herself been incarcerated in the past, she emphasized that the HIV related needs of transgender women in prisons were not being met, including access to ART and prevention commodities. A third transgender woman raised some of the challenges faced by other transgender women in her community in accessing treatment, explaining that stigma and discrimination in health-care settings and low levels of knowledge around ART within the transgender community commonly prevent transgender women from accessing treatment after testing HIV positive.

Among the majority of interviewees who were HIV negative, several people raised concerns around the possible interactions between ART and hormone therapy and the effectiveness of both treatments if taken together. One individual explicitly questioned whether he would be willing to go on ART, given his uncertainties around possible interactions. Many transgender individuals perceived the lack of guidance from the health-care profession on ART for individuals on hormones as a major challenge. A general sense of anxiety and concern was evident in participants' discussions around ART.

To inform the Consolidated guidelines on HIV prevention, diagnosis, treatment and care for 28 key populations development process.

"I don't know how effective treatment is when one is on hormones... I do think that this information is necessary, because in the event that I found that I am positive, [the] next question I ask myself is do I want to spend another sum of money being on another medication for the rest of my life, just like the hormones? So unless it's proven, I don't see the importance or the urgency for me to go on ART."

Transgender man, 29, Singapore

"I think when we talk about HIV, it should take into account what are the medications that we are on; what are the possible risks, what are the possible interactions when somebody goes onto ARV treatment as a trans person. The medical practitioners should be able to sit down with them and tell them: Seeing as you are on hormones, and now you are going onto ARVs, these are the risks, these are the considerations. That should be discussed. Definitely it's about a comprehensive package of health."

Transgender woman, 31, South Africa

Supportive factors and enablers

Those individuals who were taking ART were asked to discuss factors which they believed supported adherence to ART. Being empowered and educated around ART and feeling comfortable to discuss potential concerns with a health-care professional were seen as important factors for enabling transgender people's adherence to ART.

"I think for trans women who are HIV positive and have been conscientious about their health, who have been empowered... who are accessing medical services and who have a doctor and who are taking medication, they continue to do that because they are empowered like that... I think once a trans woman is able to get comfortable with a doctor and is comfortable enough to listen to the doctor and to take their medications regularly, then they continue to go to the doctor regularly."

Transgender woman, 44, United States

Topic 5: Hormone treatment

SUMMARY BOX: Hormone treatment

Challenging factors and barriers:

- An overall lack of gender transition services through the public health system was reported as a major barrier to accessing hormone treatment.
- The large majority of transgender individuals perceived doctors and health professionals as having little knowledge about hormone use and thus being of little value in aiding their hormone treatment.
- Accessing hormones through the public health system was repeatedly described as costly, time-consuming, unhelpful and stigmatizing. In some instances, the public health system even denied the individual's choice to transition.
- The large majority of transgender people interviewed reported engaging in self-medicated hormone therapy as a consequence of the above barriers.
- Transgender individuals who self-medicate voiced major concerns about potential harmful side-effects of unmonitored hormone treatment, as well as about the sustainability/availability and quality of hormones acquired on the black market.
- Some transgender individuals are unable to access any sustainable source of hormones in their countries.

Supportive factors and enablers:

- The outcomes of hormone treatment were described as supporting psychological wellbeing and self-actualization.
- Sharing knowledge and experiences within the transgender community and having peer support with regard to hormone treatment were important for achieving transitioning goals.
- Having access to hormones over the counter and without prescription would be welcomed by transgender women in transition.

Suggested strategies:

- Train and sensitize relevant health-care professionals to provide information, guidance or referrals to transgender individuals seeking hormone treatment, in a non-judgemental, non-stigmatizing environment.
- Reduce long waiting times created by having to go through numerous gatekeepers and lengthy psychological assessments in order to access hormone treatment through the public health system.

Attitudes towards hormone therapy

Many interviewees described their prevailing and distressing experiences of gender dysphoria. For the large majority, this resulted in an intrinsic and urgent desire to start transition. In most cases, transition started with hormone treatment. Many respondents felt that transitioning was an essential step for reducing feelings of gender dysphoria and depression, enabling integration into society, feeling complete and comfortable in one's body and allowing one to "get on with life".

"It was like [I was] a shadow of myself... it just felt like sand in my fingers, I couldn't hold on to who I was supposed to be and why I was there and how I was supposed to be presenting myself... Every day as I walked down the hallway, towards the woman's bathroom, staring at myself in this mirror, being like, "Who is that?" And that was probably the tipping point actually, weirdly; after all of the suicidal thought and all of the stupid things that I had gone through in terms of interactions with people... it was really that literally not recognizing who that was in the mirror walking down

the corridor every day. And I decided that I had three options, really: I could kill myself, which was an option. I could go back to [my home country] and try to figure out how to transition there... Or I could transition [here]. And I discounted the first two options and went with the third."

Transgender man, 31, United States

"I think if I had the opportunity to take hormone treatment, maybe my breasts and my body will be different and make me feel more comfortable with my gender identity and the way that I look... I get depression sometimes and I feel really sad sometimes... because [the way that] people see you is the way that they treat you. So I feel very, very uncomfortable right now that I don't have the opportunity to have support or some doctor to help me with... my hormone treatment to make my body look like my gender identity. There are some times that I look in the mirror and I think that I want to kill myself. That's what I feel."

Transgender woman, 36, El Salvador

"The hormones change a lot, my skin got smoother, and the shape of my face nowadays is completely changed. I have a small breast... the skin changed, the figure turn to be more feminine. Step by step... I feel good, because I wanted to be a woman."

Transgender woman, 29, Thailand

Challenging factors and barriers

The large majority of transgender individuals interviewed described access to hormones as one of the biggest health struggles they faced in everyday life. Across interviewees, a lack of information and guidance on hormone treatment from the health-care system and from medical practitioners was identified as the primary barrier. Interviewees often described high costs, complicated and lengthy processes and intrusive questioning as barriers to accessing hormones through the health-care system. Some individuals reported a complete lack of access to hormones through the health-care system.

"There is a dearth of doctors and experts on trans health care... It's quite hard to find trans friendly medical practitioners who would actually listen to you and take care of your health needs... It's also trial and error because as an endocrinologist, they really did not study hormone replacement therapy when they were in medical school, so it's an experimental phase for them to see what works and what doesn't work. And of course it's patients who will have to bear with this experimental phase."

Transgender woman, 36, Philippines

Stigma and discrimination by health professionals was a common experience encountered by the survey participants when accessing hormones through the health-care system. For example, several individuals described instances

of medical practitioners trying to “convert” them back, i.e. to make them change their mind about transitioning, or outright refusing to administer hormone treatment.

“I was supervised by a psychiatrist who was trying to change my mind... My doctor believed she can help me reconcile myself with my birth sex. So it was very difficult to speed up the process, because I was asking for hormones and she was telling me let's wait.”

Transgender man, 31, Russian Federation

As a consequence of the numerous challenges associated with accessing hormones through the public health system, most interviewees engaged in self-medicated hormone use, as this was perceived to be easier than trying to access hormones through the health-care system. The majority of these individuals reported taking oral contraceptive pills obtained at the local pharmacy. A few individuals reported using injecting hormones, which they obtained from overseas, through friends or through the Internet.

“I cannot get any access from the medical practice, medical providers, so I just read [about] it in the Internet... Most [transgender people] are doing self-medication too. It's really rare to find transwomen who [deal] with the doctor for hormone replacement therapy. It's expensive and the doctor also has stigma and discrimination.”

Transgender woman, 22, Indonesia

Concerns relating to possibly harmful side-effects of prolonged hormone use were expressed by a large majority of individuals.

“Unfortunately from what I read so far there might be some side-effects that are not symptomatic, so I am concerned that... the hormones I am taking to have the desired hormone levels are also damaging my liver.”

Transgender woman, 29, Brazil

One HIV positive transgender woman explained having stopped hormone use because she lacked medical supervision and feared health complications induced by the hormone treatment.

Several interviewees raised concerns around the availability of hormones acquired both through the informal market and through the public health system. Some participants additionally expressed worry over the quality of illicit hormones and the high cost associated with self-financing access to high-quality hormones.

“I get my hormone treatment from a local clinic... where there is no streamlined service package for trans folks...I personally have had to be very strategic, and I formed a patient-provider relationship with one of the nurses who understands the issue, but if I get there and she is on leave, then I'm really in [difficulty]... Also there are a lot of stock-outs... It really is affecting me greatly,

because if there are no hormones, it means also the hormone structure in my body is affected... it is affecting the way that I present in society, because if I go off my hormones, sometimes the hormone imbalance affects my mood, it aggravates the depression. It also relates to how confident I am, because the hormones help me in my female presentation. So if I don't have access to those hormones, it really sets me back in terms of my transition."

Transgender woman, 31, South Africa

Supportive factors and enablers

Throughout many of the interviews, a strong sense of individual and collective agency in coping with the lack of professional guidance and provision of hormones by the health system was evident. Most individuals self-medicated their hormone use, as a strategy to overcome the stigmatization and numerous barriers associated with the public health-care system. Self-medicated hormone use was seen by many as enabling "more control" over transitioning, by reducing outside determination and influence on transitioning goals. Being able to purchase hormones over the counter or through the pharmacy without prescription was welcomed by transgender women in several countries. Overall, a strong sense of community, peer support and sharing of knowledge and experiences with regards to hormone treatment were described as important supportive factors by those taking hormones.

"A group of us just decided ... we should just start experimenting on one another... The first time was really quite exciting and we all learned something together... We can control the amount of dose we want to take and we know what I'll be taking, at least.

For a lot of us it's a lot of experimenting [with] the different dosage of testosterone and seeing what it can do to us... This is something the doctor here would not be able to do; you can't request for a large amount of hormones; they would not recommend that and they would not do it. So if you are doing it yourself, you can try and see what works best for you."

Transgender man, 27, Singapore

Suggested strategies for improving hormone treatment

When asked what would improve access to hormone treatment, there was a general consensus that health professionals need to be trained to deal competently with gender transition issues, or at a minimum be able to make referrals to existing services. Some individuals also felt that doctors should be able to provide recommendations on self-administered hormone use, in order to make this common practice safer.

"We need to educate the health-care professionals so that they understand how to distribute hormones, but also understand that they can do it. Because a lot of doctors don't really know that they are allowed to do it. So they just need to be told you can do this and this is how you do it. It's just very simple. And then every

*primary health care facility should be able to distribute hormones,
because they are on the essential medicines list."*
Transgender woman, 30, South Africa

A few individuals in countries where hormones were available through the public health-care system indicated that reducing the number of gatekeepers and lengthy psychological assessments required prior to starting hormone treatment would help to significantly ease hormone access.

*"Hormone treatment in South Africa is available, but it's also very
challenging, because you have to work through the psychologist
and the social workers... Otherwise, it's not really available to
trans people, you can't walk in and say I want to have hormones,
without having had the necessary counselling or without a
prescription. The doctors won't write that prescription for you if
you have not been to the counselling and well-being
component of the transitioning process... The waiting in queues
for services in local clinics is very challenging if you are also
holding down a job."*
Transgender woman, 31, South Africa

Topic 6: Gender-affirming surgery

SUMMARY BOX: Gender-affirming surgery

- Major psychological distress was reported by those wishing to undergo surgery but unable to do so.
- Great relief and improvement to well-being was reported by those able to undergo surgery.

Challenging factors and barriers:

- Long waiting lists, arbitrary and lengthy gatekeeping mechanisms and the pathologizing nature of accessing gender-affirming treatments through the public system were seen as major challenges by a large majority of respondents.
- In several settings there was a complete lack of gender-affirming surgery through the public health system, making access impossible for those individuals unable to travel abroad for their surgery due to financial and other constraints.
- The high costs of privately financing gender-affirming surgery presented a major struggle for many.
- Overall, distrust in the technical ability of medical professionals and the quality of gender-affirming surgery, for both public and privately financed surgery, was widespread among those interviewed.
- Concerns over post-surgery complications and associated financial hardships and the potential of increased HIV related risks post-surgery were seen as barriers to undergoing surgery.

Supportive factors and enablers:

- Having the financial ability to either afford private surgery or to travel abroad for surgery was the single most important factor enabling individuals to rapidly access gender-affirming surgery.
- Seeking support and accessing resources from within the transgender community helped with sharing knowledge, experiences and recommendations regarding surgery and thus appeared to be a useful strategy to help overcome barriers.

Suggested strategies:

- Having gender-affirming surgery offered through the public-health system and reducing complex and lengthy gatekeeping mechanisms to such treatments were seen as essential for improving transgender people's physical and mental health.
- These findings suggest the need for global guidance on gender-affirming treatments and surgery to become more widely available and disseminated, and for appropriate training and capacity-building.

Challenging factors and barriers

Nearly all individuals interviewed reported major difficulties in accessing gender-affirming surgery through the public health system. The few individuals who had access to gender-affirming surgery through their public-health care system felt deterred by long waiting lists, arbitrary and lengthy gatekeeping mechanisms and the pathologizing nature of accessing such treatments through the public system.

“A lot of trans women will always tell you that they feel as if they are born in the wrong body and it's a really, really overwhelming experience to go through life with a body when you don't feel comfortable enough to shower in front of other people, to dress in front of other people and to have sex with whom you want to have sex with... So it's a really, really difficult space to be and it affects one personally. My wait on this waiting list [for gender-

affirming surgery], I won't say that my depression is because of this, but it has definitely added to the depression from which I suffer... I know some of the white trans women who have sold their houses, or have sold their car and they went to Bangkok and had the surgery... I don't have that luxury... I have been on the waiting list at one of those [centres] for the last 14 years."

Transgender woman, 31, South Africa

"The thing about the public health-care system is that it's still pathologizing and they have a mandatory two-year psychological treatment that's required. There is a big waiting line to get surgery. I have met people who have been waiting for 5 to 10 years... so it's quite frustrating... It's very unlikely you are going to get something if you don't have a diagnosis for transsexualism or gender identity disorder."

Transgender woman, 29, Brazil

Two interviewees reported an inability to access gender-affirming surgery in their country due to a complete lack of such services through the public health system.

Due to the numerous challenges associated with accessing gender-affirming surgery through the public health system, those wishing to undergo surgical transition often sought out private options for getting surgery. Among these individuals, the high costs of privately financing gender-affirming surgery were identified as a major barrier.

Many respondents had little trust in the technical ability of medical professionals and the quality of gender-affirming surgery, for both publicly and privately financed surgery. Concerns over post-surgery complications and associated financial hardships deterred several individuals from undergoing gender-affirming surgery. One participant raised concerns over the potential increased sexual risk of acquiring HIV associated with having a neo-vagina. Another participant suggested that some transgender women undergo non-medically licensed and often dangerous surgical procedures due the high costs of high-quality surgery.

"Something that I have been thinking about recently is that there is not a lot of literature that speaks to the vulnerabilities of bodies to HIV post-transition. What are the risks of having sex with this surgically created vagina? Is it the same as the anal risk; is it the same as the vaginal risk in CIS-gendered women?"

Transgender woman, 31, South Africa

Supportive factors and enablers

Some of transgender individuals interviewed strongly expressed that transition surgery was a vital pre-requisite to "get on with life" and achieve psychological wellbeing.

"[Having breast removal surgery] was amazing. That was probably the biggest barrier that I had [experienced to my sense

of self]. Going back to the idea of recognizing myself in the mirror: You can look all kinds of ways [with regard to] your face, but [once you no longer] have breasts, you are a dude. Period, end of report."

Transgender man, 31, United States

"I had to take on a loan to get my surgery, because I just wanted to get it over and done with so I can quickly get on with my life. Because it was just not possible for me to get out and get a job with the kind of body that I had and I just wasn't comfortable at all."

Transgender man, 29, Singapore

The strong desire to undergo transition appeared to drive many transgender individuals to find ways to overcome the numerous barriers to surgery. As with hormone treatment, several individuals successfully found strategies, including actively seeking the necessary information, making connections through transgender networks and peers and/or travelling overseas to undergo surgery.

Having the financial resources to pay out of pocket for surgery appeared to be the single most important factor to enable transgender individuals to have gender-affirming surgery. This financial ability enabled several individuals to access private health care in their country or to travel abroad (commonly to Thailand) to access higher-quality surgery.

"Actually, there are many clinics or hospitals where you can get the plastic surgery or the SRS [sex reassignment surgery] in Thailand. Many of them are of a high standard... There are different levels of price that you can choose and for myself my financial status at that time was quite ok. So I think I had more choice than other people who are struggling with their financial status. Most of the information is available on the Internet: the name of the hospital, of the clinic, the details of the doctor – where they graduated or the field in which they are expert."

Transgender woman, 29, Thailand

Having strong connections to transgender peers and thus benefiting from shared knowledge, experiences and recommendations regarding surgery also appeared to be a valuable strategy to help overcome barriers to surgery. A supportive and transgender-friendly clinical environment was highly valued by those individuals who had undergone surgery and led to such places being recommended further within the transgender community.

"The problem that we have to face again is that there is no licence... So it means that if you want to have surgery, you need to choose a doctor yourself. And you need to [find out] how good the doctor is also yourself. Normally we do it through the patients, some trans people network. So we just ask each other about results of surgeries and surgeons and ask them about results of surgeries."

Transgender man, 31, Russian Federation

"...I got some contacts and then they started connecting me with some other people who are like me and then we started talking and then we went for the surgery in the same hospital together [in Thailand]... It was very nice because we were able to walk out of our rooms and just talk to one another... So that's where I got more information on surgery, on hormones or how to actually take care of the scars... It was very welcoming, I would say. And it's really very warm, which is something that we won't be able to experience in normal health-care settings here."

Transgender man, 29, Singapore

Suggested strategies

Being able to access gender affirming-surgery through the public health-care system was seen by many interviewees as essential for meeting transgender people's physical and mental-health needs. Many interviewees felt that removing complex and lengthy gatekeeping mechanisms was important for improving access and reducing delays to gender-affirming surgery. The quality and professional capacity of those performing gender-affirming surgery were a common reason for concern among many of those interviewed, which suggests a need to further develop and disseminate global guidance and standards of care for gender-affirming surgery.

Conclusion

“We are in 2014 and it’s ridiculous that health care and service providers are still ignorant about who we are and what our needs are. So it is the responsibility of our policy-makers, our government, to ensure that our human and civil rights are met; and health care is a universal human right and we as trans individuals should get the services that we need.”

Transgender woman, 44, United States.

Some of the challenges that were most commonly raised across individuals and regions were a lack of transgender-specific health information and services, and stigma and discrimination from society and from health-care professionals. Past experiences of discrimination, and the fear or anticipation of experiencing discrimination, commonly influenced by the experiences of transgender peers, resulted in many transgender people actively avoiding contact with health services. Furthermore, external and internalized HIV stigma also presented barriers to transgender people seeking HIV testing and undergoing treatment. Concerns over potential interactions with hormone treatment and possible adverse side-effects of HIV related medication (including ART, PrEP and PEP) were widespread. High levels of concern about the lack of transgender-specific health information and research were evident among interviewees.

Across responses, other needs, both health-related (including physical and psychological needs) and needs beyond health (such as economic needs) were commonly prioritized over HIV related needs. These findings suggest that addressing the health- and non-health related needs that transgender people identify as priorities is a prerequisite for successfully addressing their HIV related needs.

The results of this qualitative values and preferences survey highlight the numerous challenges that persist with regard to transgender people’s access to HIV and other health services. Additionally, numerous enabling and supportive factors as well as strategies were suggested from within the transgender community. These insights present an important opportunity for developing transgender-sensitive and transgender-specific HIV and broader health services, with the goal of ensuring that transgender people are able to enjoy the highest attainable standard of health.

“The last thing that I want to say is that transgender people deserve to live with the same condition of life as any individual in any society, as any people, with the same rights, not only health rights, but in general all rights.”

Transgender woman, 35, El Salvador

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Annexes

Annex 1: 27-item Delphi online survey questionnaire

Transgender people and HIV	
Introduction to this survey	
<p>This survey aims to collect expert opinion on key issues relating to transgender people and HIV. Results from this survey will inform the design of values and preferences interviews among transgender people, which will be conducted as part of developing WHO consolidated HIV guidance for key populations.</p> <p>This survey should take around 10 minutes to complete and consists of the following five sections:</p> <ol style="list-style-type: none">1) Terminology2) Risk groups3) Risk factors4) Strategies and enabling factors5) Optional: other key issues <p>For the purpose of this survey, the following definitions will be used:</p> <p>Transgender women*: People who were assigned 'male' at birth and have a feminine gender identity and or/feminine expression.</p> <p>Transgender men*: People who were assigned 'female' at birth and have a male gender identity and or/masculine expression.</p> <p><i>Most questions refer specifically to either transgender women* or transgender men*, so please note this difference while responding to each question. Questions are kept broad and are meant to capture general trends at a global scale.</i></p>	
Basic respondent information	
<p>* 1. Please note: your personal information will be anonymous to all other respondents and will be kept confidential.</p> <p>Name: <input type="text"/></p> <p>Organisation: <input type="text"/></p> <p>Duty Station/Country: <input type="text"/></p> <p>Email Address: <input type="text"/></p>	
Terminology	
<p>Which terms do you consider most appropriate to describe the various groups of transgender people? <i>(multiple answers possible)</i></p>	

Transgender people and HIV

2. People who were assigned 'male' at birth and have a female gender identity and/or feminine expression:

Transgender woman

Trans woman

Male to female

Other (please specify)

3. People who were assigned 'female' at birth and have a male gender identity and/or masculine expression:

Transgender man

Trans man

Female to male

Other (please specify)

4. Are there other categories of transgender/ gender variant people that should be considered with regard to HIV vulnerability? (please specify and define)

Risk groups

Transgender people and HIV

*** 5. Which level of HIV risk do you associate with each group of transgender persons?**

Please check:

	Very high-risk	High-risk	Low-risk	No risk
Transgender women*	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transgender men*	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transgender women* who are sex workers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transgender men* who are sex workers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transgender women* who inject recreational drugs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transgender men* who inject recreational drugs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Adolescent transgender women*	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Adolescent transgender men*	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify and type level of associated risk)

Risk factors

The following questions focus on issues that potentially make transgender women* and transgender men* more vulnerable to HIV infection.

For each question, please give your opinion on how important/relevant you feel each issue is in terms of putting **transgender women*** and **transgender men*** at **increased risk of HIV infection?**

6. Sexual risks – Transgender WOMEN*

	Very important	Moderately important	Unimportant	Uncertain
Multiple sex partners	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Inconsistent condom use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Unprotected receptive anal intercourse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sexual intercourse under the influence of substances	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sex work	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sexual violence	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify and type importance ranking)

Transgender people and HIV				
7. Sexual risks – Transgender MEN*				
	Very important	Moderately important	Unimportant	Uncertain
Multiple sex partners	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Inconsistent condom use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Unprotected receptive anal intercourse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sexual intercourse under the influence of substances	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sex work	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sexual violence	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify and type importance ranking)				
<input type="text"/>				
8. Injecting risks – Transgender WOMEN*				
	Very important	Moderately important	Unimportant	Uncertain
Injecting drug use (of recreational drugs)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Non-injecting drug use (of recreational drugs)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Injecting hormone use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Injecting silicon use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify and type importance ranking)				
<input type="text"/>				
9. Injecting risks – Transgender MEN*				
	Very important	Moderately important	Unimportant	Uncertain
Injecting drug use (of recreational drugs)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Non-injecting drug use (of recreational drugs)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Injecting hormone use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Injecting silicon use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify and type importance ranking)				
<input type="text"/>				

Transgender people and HIV				
10. Transitioning – Transgender WOMEN*				
	Very important	Moderately important	Unimportant	Uncertain
Sexual reassignment surgery (SRS) procedures carried out in non-registered/non-medically supervised settings	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Interactions between cross gender hormone therapy (CGHT) and anti-retroviral treatment (ART)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Post-operative complications and infections (among transgender women* who have undergone SRS)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify and type importance ranking)				
<input type="text"/>				
11. Transitioning – Transgender MEN*				
	Very important	Moderately important	Unimportant	Uncertain
Sexual reassignment surgery (SRS) procedures carried out in non-registered/non-medically supervised settings	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Interactions between cross gender hormone therapy (CGHT) and anti-retroviral treatment (ART)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Vaginal dryness and associated risk of injury (among non/pre-operative transgender men* taking hormones)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Post-operative complications and infections (among transgender men* who have undergone SRS)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify and type importance ranking)				
<input type="text"/>				

Transgender people and HIV				
12. Access to prevention programs and health services - Transgender WOMEN*				
	Very important	Moderately important	Unimportant	Uncertain
Lack of transgender women* specific health services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Discrimination of transgender women* by health workers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lack of tailored HIV prevention and treatment programs for transgender women*	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Low levels of HIV related knowledge among transgender women*	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Low levels of HIV testing (and resulting knowledge of HIV status)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Low demand for health services by transgender women* (as a result of discrimination and perceived lack of services)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify and type importance ranking)				
<input type="text"/>				
13. Access to prevention programs and health services - Transgender MEN*				
	Very important	Moderately important	Unimportant	Uncertain
Lack of transgender men* specific health services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Discrimination of transgender men* by health workers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lack of tailored HIV prevention and treatment programs for transgender men*	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Low levels of HIV related knowledge among transgender men*	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Low levels of HIV testing (and resulting knowledge of HIV status)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Low demand for health services by transgender men* (as a result of discrimination and perceived lack of services)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify and type importance ranking)				
<input type="text"/>				

Transgender people and HIV				
14. Socio-economic risks - Transgender WOMEN*				
	Very important	Moderately important	Unimportant	Uncertain
Economic marginalization	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Homelessness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Social isolation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Physical abuse and violence	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Discrimination from and limited access to education	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Low prioritisation of HIV amongst other competing health needs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify and add importance ranking)				
<input type="text"/>				
15. Socio-economic risks - Transgender MEN*				
	Very important	Moderately important	Unimportant	Uncertain
Economic marginalization	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Homelessness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Social isolation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Physical abuse and violence	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Discrimination from and limited access to education	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Low prioritisation of HIV amongst other competing health needs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify and add importance ranking)				
<input type="text"/>				
16. Structural Barriers - Transgender WOMEN*				
	Very important	Moderately important	Unimportant	Uncertain
Transphobia, stigma and discrimination	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Criminalization	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lack of legal recognition of gender status	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Incarceration	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify and add importance ranking)				
<input type="text"/>				

Transgender people and HIV				
17. Structural barriers – Transgender MEN*				
	Very important	Moderately important	Unimportant	Uncertain
Transphobia, stigma and discrimination	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Criminalization	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lack of legal recognition of gender status	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Incarceration	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify and type importance ranking)				
<input type="text"/>				
18. Co-morbidities – Transgender WOMEN*				
	Very important	Moderately important	Unimportant	Uncertain
STI co-infections	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mental health problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
TB	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
HBV	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
HCV	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify and type importance ranking)				
<input type="text"/>				
19. Co-morbidities – Transgender MEN*				
	Very important	Moderately important	Unimportant	Uncertain
STI co-infections	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mental health problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
TB	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
HBV	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
HCV	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify and type importance ranking)				
<input type="text"/>				
Strategies and enabling factors				
<p>The following questions focus on transgender-specific strategies to address HIV vulnerabilities. Other strategies are already universally recommended for all key populations, including transgender people. These include condom programming, testing and counseling, treatment, prevention and control of sexually transmitted infections, needle and syringe programming, opioid substitution treatment and others.</p> <p>Which of the following are important strategies for addressing HIV vulnerabilities among transgender women* and transgender men* specifically?</p>				

Transgender people and HIV				
20. ART related prevention – Transgender WOMEN*				
	Very important	Moderately important	Unimportant	Uncertain
Pre-exposure prophylaxis (PrEP)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Post-exposure prophylaxis (PEP)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Early initiation of ART for all transgender women*	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Early initiation of ART for serodiscordant couples	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify and type importance ranking)				
<input type="text"/>				
21. ART related prevention – Transgender MEN*				
	Very important	Moderately important	Unimportant	Uncertain
Pre-exposure prophylaxis (PrEP)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Post-exposure prophylaxis (PEP)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Early initiation of ART for all transgender men*	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Early initiation of ART for serodiscordant couples	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify and type importance ranking)				
<input type="text"/>				
22. Health service provision and delivery – Transgender WOMEN*				
	Very important	Moderately important	Unimportant	Uncertain
Transgender women*-specific behavior change counseling and information	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transgender women*-specific facility-based health services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transgender women*-specific facility-based outreach	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transgender women*-specific safe spaces (drop-in centers)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transgender women*-specific community-based (peer) outreach	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transgender women*-specific social media interventions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify and type importance ranking)				
<input type="text"/>				

Transgender people and HIV				
23. Health service provision and delivery - Transgender MEN*				
	Very important	Moderately important	Unimportant	Uncertain
Transgender men*-specific behavior change counseling and information	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transgender men*-specific facility-based health services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transgender men*-specific facility-based outreach	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transgender men*-specific safe spaces (drop-in centers)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transgender men*-specific community-based (peer) outreach	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transgender men*-specific social media interventions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify and type importance ranking)				
<input type="text"/>				
24. Transgender-specific interventions - Transgender WOMEN*				
	Very important	Moderately important	Unimportant	Uncertain
Cross gender hormone therapy (CGHT)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sex reassignment surgery (SRS)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify and type importance ranking)				
<input type="text"/>				
25. Transgender-specific interventions - Transgender MEN*				
	Very important	Moderately important	Unimportant	Uncertain
Cross gender hormone therapy (CGHT)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sex reassignment surgery (SRS)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify and type importance ranking)				
<input type="text"/>				

Transgender people and HIV				
26. Structural interventions – Transgender WOMEN*				
	Very important	Moderately important	Unimportant	Uncertain
Community empowerment and peer-led support interventions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Creation of an enabling environment for transgender people (non-discrimination laws, policies and legislation)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Inclusion of transgender women* in research and clinical trials for HIV prevention and treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify and type importance ranking)				
<input type="text"/>				
27. Structural interventions – Transgender MEN*				
	Very important	Moderately important	Unimportant	Uncertain
Community empowerment and peer-led support interventions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Creation of an enabling environment for transgender people (non-discrimination laws, policies and legislation)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Inclusion of transgender men* in research and clinical trials for HIV prevention and treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify and type importance ranking)				
<input type="text"/>				
Key issues for HIV among transgender people.				
28. Please add any other important topics/issues which were not covered or any other points which you would like to raise? (optional)				
<input type="text"/>				
Thank you for participating in Round 1 of the "transgender people and HIV" ...				

Transgender people and HIV

Your responses will help ensure that the most important topics are covered in the values and preferences interviews with transgender people.

You will be contacted again in the following weeks with an **invitation to participate in the Round 2** of this survey.

Please contact consultant Mira Schneiders (schneidersm@who.int) with any further questions.

Annex 2: Recruitment text included a link to a short online survey

Dear XXX,

I am working at the HIV Department at the World Health Organization in Geneva. We are in the process of updating guidelines on HIV prevention, treatment and care for key populations, including specific issues for transgender people. For this, we want to **take into account the voices of transgender women and men**, by documenting some of the diverse experiences, values and preferences from around the world.

WHO is preparing to conduct **anonymized in-depth interview** with a small number of transgender individuals who are interested in sharing some of their personal stories. Specifically, we hope to learn more about how transgender women and men may be affected by **HIV and other health issues**, what their specific HIV related risks, challenges and needs are, and what successful strategies may exist to reduce HIV vulnerability.

If you are interested to participate in an in-depth interview, please fill out this short survey:

ACCESS THE SHORT SURVEY HERE: <https://de.surveymonkey.com/s/3DBX73D>

All personal information and answers given in this short survey will be kept **confidential** and will only be used for the purpose of selecting individuals for the in depth-interviews.

Further information to survey participants:

What will happen if I fill out this survey?

If you fill out this survey, you are letting us know that you are interested in being interviewed. As we are trying to get a global picture and can interview only a small number of transgender women and men, we will select people from different regions of the world and with a range of different experiences to take part in these interviews. Therefore, you may or may not be invited for an interview if you fill out this short survey. You will hear back from us within one week. We thank you for filling in this short survey and apologize in advance if you do not become selected for an in-depth interview.

What will happen if I am invited to take part in an interview?

If you are invited to take part in the interviews, we will contact you with more information regarding the interviews. Interviews will be conducted by telephone or Skype at a time most convenient for you. The interview will last around one hour and will be voice recorded and then typed up electronically. The information you provide is confidential and only the interview team will have access to your personal information. Your response will be anonymous in that your personal information will not be matched with anything you say in the interviews.

Before we start the interview, you will be given more details about the interviews and we will ask for your verbal informed consent.

Do I have to become involved?

To inform the Consolidated guidelines on HIV prevention, diagnosis, treatment and care for **54** key populations development process.

Participation in this short survey and in the in-depth interviews is strictly voluntary and you do not have to become involved at all. You can also decline to take part at any point later in time without explanation and without further consequences for you.

Unfortunately we are unable to pay for your involvement in this survey or the subsequent in-depth interview. We are very grateful for your time and support.

Annex 3: Online socio-demographic survey for interview participants

Transgender people short survey

Introduction to this survey

WHO is preparing to conduct anonymised in-depth interviews with a small number of transgender individuals to inform the development of HIV guidelines for key populations.

By filling out this survey, you are letting us know that you are interested in being interviewed. As we can interview only a small number of transgender women and men from different world regions and with a range of experiences, you may or may not be invited for an interview if you fill out this survey. We apologise in advance if you do not become selected for an in-depth interview and thank you for your support.

Confidential survey:

Any identifying information you provide in this survey will be kept **confidential** and can only be accessed by the interview team at WHO. The information you provide below will not be shared and is only used for purposes of selecting interview candidates.

Participation in this short survey is strictly voluntary and you do not have to answer any of the questions you do not want to.

Basic information (1/3)

Any identifying information you provide in this survey will be kept **confidential** and can only be accessed by the interview team at WHO. The information you provide below will not be shared and is only used for purposes of selecting interview candidates.

***1. Personal information**

Name:

Age:

E-mail address:

Country of current residence:

Primary occupation/primary source of income:

***2. How would you describe your level of english?**

Very good (*I speak and understand English fluently.*)

Good (*I speak and understand well with occasional mistakes.*)

Intermediate (*I can speak and understand reasonably well with some problems.*)

Elementary (*I can say and understand a few things in English.*)

Beginner (*I do not speak any English.*)

If "Elementary" or "Beginner": is there another language(s) you want to be interviewed in?

Gender identity (2/3)

Transgender people short survey

***3. What is your current gender?**

- Male
- Female
- TransMale/Transman
- TransFemale/Transwoman
- Genderqueer
- Decline to state
- Other

Other (please specify)

***4. What sex were you assigned at birth?**

- Male
- Female
- Decline to state

***5. Sexual orientation (tick all that apply)**

Who do you feel physically, romantically, and/or emotionally attracted to?

- Attracted to Transwomen
- Attracted to Transmen
- Attracted to cis-women (non-Transwoman)
- Attracted to cis-men (non-Transwoman)
- Attracted to Genderqueer people
- Not sure
- None
- Decline to state
- Other

Other (please specify):

Information related to HIV (3/3)

As we want to ensure that our interviews take into account the experiences of people at risk of HIV or living with HIV, we will now ask you some questions that relate to HIV. This will help us select a range of individuals with different HIV-related characteristics for the in-depth interviews.

You do not have to answer any of these questions if you do not want to.

Transgender people short survey

6. Have you ever been tested for HIV? (optional)

- Prefer not to say
- Yes
- No
- Not sure

7. What is your HIV status? (optional)

- Prefer not to say
- Positive
- Negative
- Don't know

8. Have you had any kind of gender affirming surgery/ sex reassignment surgery? (tick all that apply)

- Prefer not to say
- None
- Top (chest) surgery
- Bottom (genital) surgery
- Other

Other (please specify):

Thank you!

Thank you very much for completing this short survey.

The information you provided will be kept confidential and will not be shared.

As we are trying to capture a diverse range of experiences and can only interview a small number of transgender women and men, we will select people from different regions of the world and with a range of different experiences to take part in these interviews.

We will contact you within the next week to let you know if you have been selected for the in-depth interview.

We are very grateful for your time and support.

Please contact Mira Schneiders (schneidersm@who.int) with any questions you may have.

Annex 4: Interview guide

GENERAL QUESTION STRUCTURE

The following broad/open ended questions and probes will be applied to each interview topic:

1) Personal experience

- *Can you tell me a bit about your experience with xxx?*
- *What was it like xxx?*
- *Could you give me some examples from your experience?*
- *How did that make you feel?*
- *How do you think other people in your trans community experience xxx?*
- *How has xxx impacted your life?*
- *How accessible is xxx in your setting?*

2) Benefits and Enablers

- *What motivates/motivated you to do xxx?*
- *How do you address/access xxx?*
- *What enabled/helped you in this situation to xxx?*
- *What do you think are the benefits of xxx?*
- *How effective do you think xxx is?*

3) Barriers and Challenges

- *What were some of the challenges to xxx?*
- *What do you perceive as the main barriers to xxx?*
- *Did you experience any difficulties in this situation?*
- *What prevented you from doing/accessing xxx?*

4) Suggested strategies/ solutions

- *What would help/assist you in/to get/access xxx?*
- *What information would you need to do/get xxx?*
- *What would be most beneficial/helpful to you in this situation?*
- *How do you think this problem could be addressed/solved/improved?*
- *How could things be made easier for you in this situation?*
- *How should xxx best be offered to transgender people in xxx?*

In case of questions to interviewer during interview:

- *That's a good question; I will get back to it at the end of the interview. For now I am interested in your experience...*
- *I will make a note of question and answer it at the end of the interview (if possible, or else say you will follow up via email with an answer).*

INTRODUCTION AND VERBAL CONSENT

1. Read consent form, answer any questions and then ask participant for verbal consent (start recording at this time)
2. Commence the interview

SECTION 1 - SOCIO-DEMOGRAPHIC INFORMATION

If already gathered in online survey, don't repeat:

Name:

Age:

E-mail address:

Country of residence:

Primary occupation/primary source of income:

Level of English:

Current gender:

Sex assigned at birth:

Sexual orientation:

Ever tested for HIV:

HIV status:

Gender reassignment surgery:

SECTION 2- HIV PREVENTION

HIV KNOWLEDGE AND ACCESS TO PREVENTION SERVICES

ICE BREAKER

First, I'm curious to hear a bit about your involvement in the trans community and with HIV issues more broadly.

What is your main source of information on HIV prevention (e.g. Internet, transgender friends and community, organizations working in HIV, health centres)

TRANSITIONING

Now, I want to ask you about transitioning. You said in the survey that you have had xxxx....

Tell me a bit about your experience transitioning? (e.g. age, where, how did you start)

(if bottom surgery) You mentioned in the survey you had xxx:

- *did you experience and post operative complications?*

How has transitioning impacted your life?

Did you face any challenges during this process?

If not mentioned yet; ask specifically about use of:

- Hormones (injection risks)
- MtF only: Silicone or other soft tissue fillers
 - What, how (injected?- if so access to clean needles?)
- Gender-affirmative surgery
 - Why desired or not, ease of access, what and how – medically supervised?

How would you ideally like to be able to access these services?

Do you see a role for integration of HIV services with other trans-specific health services (e.g. hormone treatment/gender reassignment surgery)?

SEXUAL HEALTH

Now, I would like to find out a bit more about your sexual health. If any of these questions make you feel uncomfortable and you prefer not to answer them, that is totally fine, just tell me so.

Could you tell me a bit about your sexual health needs?

So in the survey you indicated that you feel physically, romantically and/or emotionally attracted to XXXX.

Do you use prevention commodities to prevent HIV and STIs?

- *How easy is it for you to access these?*
- *(if discordant relationship) explore PrEP, PEP, early initiation of ART*

MENTAL HEALTH AND DRUG USE

Is access to clean needles and syringes a concern for you? (e.g. for use of injecting hormones, silicone, recreational drugs)

- *(if yes) explore access to NSP and OST*
- *(if no) access in the wider community*

How easily available are clean needles in your country/city and where do you get them from?

SECTION 3- TESTING AND COUNSELLING (only for those who have been tested)

You indicated on the survey that you have been tested for HIV and that your result is xxx

Can you tell me a bit more about your experience(s) getting tested?

- *Place (e.g. public clinic, community based, private, NGO)*
- *Did you go alone or with a partner/friend*
- *How did you feel getting tested there?*
- *Can you tell me about getting the result?*

SECTION 4- TREATMENT AND CARE (only for HIV +)

- *What happened after getting the result (e.g. did you get referred to HIV treatment and care services)?*
- *What were you told about treatment?*
- *What do you know about when you start ART?*
 - *Early initiation of treatment, why yes or no*

In an ideal world, what would HIV services be like for you?

- *Do you prefer to have health services that are specific to trans people only or integrated into general health services*

TREATMENT AS PREVENTION (only for HIV -)

Have you ever heard of pre-exposure prophylaxis (PrEP) or post-exposure prophylaxis (PEP)?

Have you ever used a medication or pill before (called PrEP) or after (called PEP) a time when you felt you were at risk of exposure to HIV?

- a. *What have you heard about PrEP or PEP?*
- b. *Tell me a bit more about your experiences using xxx?*
- c. *What did you think the benefits were?*
- d. *Did you experience any difficulties with using xxx?*
- e. *Is there much information available on PrEP/PEP in your community?*

SECTION 5- OTHER HEALTH CONCERNS

Are there any other health topics or concerns, HIV or other that are important to you/ OR the broader transgender community?

e.g.

1. *Co-morbidities (TB, HBV, HCV, STI)*
2. *Opportunity to raise any other topics/concerns*

DEBRIEFING

Thank you very much for taking part in this interview. WHO really appreciates your time and willingness to share very personal experiences, thoughts and feelings.

Once we collect all the data, it will be analysed and a report will be written and a copy sent to you (probably in late early March 2014).

Reminder: *We will not use any identifying information about you in this report.*

Would you be interested in being emailed a copy?

Yes _____ No _____

Further contact/questions/concerns: contact details provided

Annette Verster VersterAn@who.int

Would you mind if I contacted you later in case of any follow up questions?

Yes _____ No _____

ADDRESS QUESTIONS THAT CAME UP IN INTERVIEW

Either answer question or say "I want to give you an accurate answer so let me check that question and get back to you soon with the answer".

Annex 5: Participant Information Sheet

INFORMATION SHEET VERBAL INFORMED CONSENT TO PARTICIPATE IN

Transgender people and HIV: Values and Preferences Interviews

We will be conducting interviews with transgender men and women to discover their HIV and other health related experiences and needs. This Information Sheet explains the interview process in detail to you in writing. Before the phone-interview will be conducted, the interviewer will again explain this information to you verbally.

We would like you to ask ANY question about any part of the interviews that you do not fully understand. After you understand all aspects of the interview, we will ask you to decide if you want to participate or not. Once you have verbally agreed to take part on the phone, we will give you a written copy of this Information Sheet to keep.

It is important that you understand that your participation in this interview is entirely voluntary; you do not have to take part if you do not want to.

Why are these interviews being done?

The WHO HIV Department is conducting interviews to learn more about HIV related needs among transgender women and men, globally. Specifically, we hope to explore HIV related risk behaviours, experiences with HIV and other health-care services, and the challenges and opportunities of successful HIV prevention, treatment and care among transgender people. This information will be considered by WHO in developing recommendations for HIV guidance for key populations, including transgender people. You are being asked to participate because you are a transgender individual and have expressed an interest in being interviewed by recently completing our short online questionnaire entitled "Transgender people short survey".

How many people will take part in these interviews?

Approximately 20 transgender individuals overall will be in this study.

What will happen if I decide to be in an interview?

If you agree to participate in this study:

1. You will be asked to provide us with a telephone number or Skype account name, at which you can be reached and a date and time which is convenient to you.
2. The interviewer will call you at the agreed date and time and talk to you on the phone for about one hour. The interviewer will be semi-structured, in that the interviewer will ask you some guiding questions and will give you the opportunity to respond freely and discuss any topics, which you feel are important to you.
3. The interviews will be voice recorded and then typed up on the computer by the interviewer. You will be assigned an interview ID-number by the interviewer and only the interviewer will have access to the file, which

To inform the Consolidated guidelines on HIV prevention, diagnosis, treatment and care for 63 key populations development process.

matches your ID-number to your name. The interview ID-number will ensure that your name will not be matched with anything you say later.

4. The content of the transcribed interviews will then be analysed by the interviewer and a report of the finding will be written and published. The report will include quotes from your and other interviews. No identifying information will be included in this report, but direct quotes from the interview will be used.

What risks can I expect from being in an interview?

There are some possible risks or discomforts related to being in this study. In particular, the interview includes personal questions about your past and current sexual activity, drug use and about transitioning, and you may feel shy or uncomfortable answering some of them. You do not have to answer any questions that you do not want to and can simply say so during the interview.

Are there any benefits from taking part in an interview?

No. There are no real benefits to you. WHO will learn more about how transgender women and men are affected by HIV and other health issues, in order to better understand their needs for HIV prevention, treatment and care.

Will all information about me be kept private?

Participation in any research may involve a loss of privacy, but information about you will be handled as confidentially as possible. A study file with your interview ID-number will be created for you electronically, and the recording of the interview as well as the transcript of the interview will be kept in your study file. Only the interviewer and the team will have access to this file. After the analysis of the interviews is completed, all personal identifying information and recordings of interviews will be deleted. Transcribed version of the interviews will be stored electronically and will be published as part of a report. Any published information in writing or presented at scientific meetings will not include your name or other personal identifying information.

Will I be paid to be in this interview?

No, you will not receive any compensation for taking part in this interview.

How long will the interview be if I decide to participate?

If you decide to participate, you will have one telephone interview, which will take around 60 minutes (1 hour).

Do I have to take part in these interviews?

Taking part in these interviews is your choice and completely voluntary. You may choose either to take part or not to take part. If you decide to take part in this interview, you may leave the interview at any time and without explanation. No matter what decision you make, there will be no penalty to you.

Who can answer my questions about this interview?

If you have questions or concerns about these interviews, please contact the interviewer, Mira Schneiders at schneidersm@who.int or her supervisor, Annette Verster at VersterAn@who.int.

PARTICIPATION IN THESE INTERVIEWS IS VOLUNTARY. YOU CAN DECLINE TO PARTICIPATE IN THE INTERVIEW AT ANY POINT, WITHOUT ANY PENALTY OR LOSS OF RIGHTS.