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# Values and preferences of key populations: consolidated report

This report was prepared to inform the World Health Organization Consolidated guidelines on HIV prevention, diagnosis, treatment and care for key populations development process.

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**Mary Henderson** (WHO consultant), provided the consolidated analysis of values and preferences and this final report. **Alice Armstrong** (WHO consultant) supported Mary Henderson and contributed through the consolidation and analysis of the young key population components of the consolidated report. Alice Armstrong also coordinated the collection of young key population values and preferences processes performed by numerous youth and community organisations as part of the development of the HIV and young key population technical brief series and included within this report (see listed below and Annex 6).

The individuals, community networks and organizations that carried out the values and preferences work are listed in table 1 within the methods section. Reference to their work is also listed below:

- **Caitlin Kennedy & Virginia Fonner.** Pre-exposure prophylaxis for men who have sex with men: a systematic review ***(see Annex 1)*** & Pre-exposure prophylaxis for people who inject drugs: a systematic review ***(see Annex 2).***
- **The Global Forum on MSM and HIV (MSMGF).** Values & preferences of MSM: the Use of Antiretroviral Therapy as Prevention ***(see Annex 3.1).***
- **Mary Henderson.** Values and preferences of people who inject drugs, and views of experts, activists and service providers: HIV prevention, harm reduction and related issues ***(see Annex 3.2).***
- **Mira Schneider.** Values and preferences of transgender people: a qualitative study ***(see Annex 3.3).***
- **UNAIDS.** Sex workers' hopes and fears for HIV pre-exposure prophylaxis: recommendations from a consultation meeting. Forthcoming 2014.
- **AVAC & GNP+.** What do key populations in South Africa think about PrEP and TasP? Understanding the needs of key populations in the context of using ARVs for prevention. Forthcoming 2014.
- **Youth Research Information Support Education (Youth RISE) and Joint United Nations Programme on HIV/AIDS**. Experiences of young people who inject drugs and their challenges in accessing harm reduction services. Forthcoming 2014.
- **Youth Voices Count.** Policy brief on self-stigma among young men who have sex with men and young transgender women and the linkages with HIV in Asia. Bangkok: Youth Voices Count; 2013.
- **HIV Young Leaders Fund.** "First, do no harm:" an advocacy brief on sexual and reproductive health needs and access to health services for adolescents 10–17 engaged in selling sex in the Asia Pacific. New York (NY): HIV Young Leaders Fund; forthcoming 2014.
- **Youth Leadership, Education, Advocacy and Development Project.** Access to Youth Friendly HIV services for Young Key Affected People (YKAP) in Asia. unpublished data.
- **United Nations Population Fund**. Community consultations with young key populations, unpublished data.

**Sincere thanks go out to all those involved in the consultations.**

# 1. Background

WHO is consolidating existing guidance for key populations and including important new recommendations to address issues for which new evidence or experience have become available. The consolidated guidance will consider a range of elements that are common across all key populations as well as highlighting specific issues that are unique to individual population groups. It will guide and support countries to plan, develop and monitor acceptable and appropriate programmes that include a range of issues that affect members of key populations and their ability to access HIV prevention, treatment and care, and harm reduction services.

Key populations covered by this work include men who have sex with men (MSM), transgender people (TG), people who inject drugs (PWID), sex workers (SW), prisoners, migrants and adolescent and young people from key population groups (YKP).

An essential element of this work has been engaging and partnering with key population groups and networks to understand their values and preferences related to HIV and harm reduction service provision, to learn from their experiences and to incorporate their suggestions for building on existing effective programming. A number of global and regional processes explored the values and preferences of different key populations around different themes. This summary report highlights key messages that are common across all, or a number of, key population groups and notes other specific issues that are of particular concern to individual groups.

The results of this consolidation are presented in tables organized into five main topics:

- **Cross-cutting issues** (includes human rights, protection, criminalization, vulnerability, service delivery issues, social and interpersonal issues, access to services)
- **HIV prevention** (includes HTC, commodities, services and information)
- **Testing modalities** (includes consideration of access, clinic-based vs mobile and outreach services, and self- testing)
- **ART** (includes treatment and care services, ART for prevention)
- **Harm reduction** (includes the comprehensive package and related issues)

## 2. Methods

This consolidation comprises findings from 13 studies, group consultations, online surveys or literature reviews conducted from 2012–2014. Those are listed with authors in table 1.

**Table 1. Contributing individuals, networks and organisations to the values and preferences**

| KEY POPULATION | AUTHOR (ORGANIZATION OR INDIVIDUAL) | TOPIC(S) |
|---|---|---|
| YKP | 1. Youth Rise (YPWID) | Comprehensive harm reduction package |
| | 2. HIV Young Leaders Fund (YP who sell sex) | Experiences of young people who sell sex; exploring programmatic approaches and suggestions from YSW |
| | 3. Youth Voice Count (YMSMTG) | Self –stigma, HIV and human rights |
| | 4. UNFPA (YKP) | Access/availability to services and support |
| | 5. Youth LEAD (YKP) | Accessibility of services |
| MSM (multi-country) | 6. MSMGF | HTC, access to services, ART for prevention, discrimination, violence and legal issues |
| MSM (multi-country) | 7. Caitlin Kennedy (JHU) | PrEP (part of systematic review) |
| PWID (Ukraine) | 8. Caitlin Kennedy | PrEP (part of systematic review) |
| PWID (multi-country) | 9. Mary Henderson (independent consultant) | HIV prevention, ART for prevention, harm reduction, community distribution of naloxone |
| PWID (Vietnam) | 10. Kristine Buchman and Masaya Kato (WHO, WPRO) | Early ART and periodic HIV testing |
| SW (South Africa) | 11. Wits Reproductive Health Institute | PrEP |
| KP (South Africa) | 12. GNP+ and AVAC | PrEP and TasP |
| Prisoners | 13. Amee Schwitters (CDC) | Condoms, drug dependence treatment, HTC |

Data from the reports were entered into a spreadsheet; findings were categorised by key population group; country/region; theme; values, views or experience; and preferences or recommendations. Common values and preferences across groups as well as issues specific to individual groups were identified through qualitative grouping and analysis. Findings reflecting the views of clear majorities of respondents or most of the KP groups are listed as common values and preferences or key messages. However, due to the variations in

themes explored by different studies and reviews, analysis of findings may require further data collection to be conclusive.

# 3. Summary of key findings

The following tables present the common themes across all or most key population groups, and issues unique to specific groups or regions within each main topic area.

## 3.1 Cross-cutting issues

**Table 2. Values & preferences across key population groups: cross-cutting issues**

| COMMON VALUES / VIEWS / EXPERIENCES | COMMON PREFERENCES / RECOMMENDATIONS | ISSUES SPECIFIC TO INDIVIDUAL GROUPS, COUNTRIES or REGIONS |
|---|---|---|
| **1. Criminalization of key populations and specific practices associated with these communities undermines HIV prevention and harm reduction**; threat of harassment, detention is a major barrier to uptake of services; possession of condoms, drug paraphernalia used as 'evidence' of illegal behaviour. | **Legal reforms and protections needed** to reduce fear and to facilitate utilization of services and ensure that HIV prevention, treatment and care, and harm reduction are accessible and effective.<br><br>***WHO requested to take a strong position on this issue in partnership with other relevant bodies (UNODC, UNAIDS, and other relevant partners).*** | **PWID** considered by many to be the most marginalized of all KP groups; decriminalization necessary to support uptake of services, retention in care and adherence to ART.<br><br>Criminalization of HIV in some countries contributes to secrecy and leads to targeting of **all KP** and abusive application of laws, entrapment and inappropriate charges (aggravated assault, non-disclosure of HIV status) – ultimately, this fuels the epidemic in these countries. |
| **2. Lack of protection**; widespread experience of harassment, financial exploitation and physical and emotional abuse by local police. | Advocacy and legal reforms needed to help change the way that KPs are viewed and treated by law enforcement as well as by society.<br><br>Accountability/enforcement mechanisms need to be developed and implemented to ensure that individuals' rights are protected.<br><br>Access to legal services. | In Nepal, **YPWID** can be abducted with parental consent and forced into abusive and long-term 'rehabilitation programmes'.<br><br>In some Middle East and North Africa (MENA) countries, **PWID** who seek services are reported to the police; bribes are paid to get overdose treatment without reports to police; PWID die of OD when peers fearful of calling for emergency services. |
| **3. Critical enablers not sufficiently in place for KP**:<br>• Protection of human rights<br>• Social and economic inclusion (including racism and loss of cultural identity in some settings where certain communities confront extreme social and economic exclusion) | ***WHO requested to take a strong position on broader societal issues when engaging with countries at highest levels of government.*** | |

| COMMON VALUES / VIEWS / EXPERIENCES | COMMON PREFERENCES / RECOMMENDATIONS | ISSUES SPECIFIC TO INDIVIDUAL GROUPS, COUNTRIES or REGIONS |
|---|---|---|
| • Poverty, hunger homelessness common across regions<br>• Lack of access to basic health services, including mental health and psychological follow-up<br>• Stigma and discriminatory practices by key duty bearers in society (health system, law enforcement, educators) | | |
| **4. Health provider issues:** Stigma, discrimination, judgmental attitudes, harassment, vocal hostility, complicity with police, lack of sensitivity, lack of understanding of KP-specific issues.<br><br>Breaches of confidentiality, with colleagues, with families of patients, with law enforcement. | Training, mentoring and professional support urgently needed for providers serving key populations.<br><br>Guaranteed confidentiality required to establish trust and to encourage uptake of services.<br><br>Peer-led services accompanied by peer support are considered the most acceptable and the most effective for all KP groups. | Former or active injecting drug users often barred from providing services; this deprives **PWID** of valuable support and services from people with lived, shared experience.<br><br>In some countries, training and support are urgently needed at lower levels of the health system where providers have less capacity, professional support and understanding of KP issues; often little knowledge of updated recommendations that may affect KP. |
| **5. General lack of information about human rights, legal services, interventions**. | A wide range of communication channels and media (including for low-literacy audiences) should be used to communicate lifesaving and other practical information for KP, including community-specific info. | **YKP** need education on their rights and mechanisms for reporting rights violations.<br>*(Note: Not mentioned in other studies, but likely a common issue across all KP groups.)* |
| **6. Lack of KP-specific services.** | All KP feel that services specific to their needs are preferable to services designed for the general public; at the same time, they request that certain services, such as ART, be delivered alongside other health services in order to remove the stigma attached to HIV-related services.<br><br>Outreach and mobile services preferred. | Services tailored for **YKP** are urgently needed. In general, YKP have a sense of being young and healthy, and they have a different perception of their risks and their needs for services; youth-targeted outreach and mobile services preferred. YKP reluctant to seek services with older members of the KP groups. Need to address the needs of YKP in ways that encourage utilization of services and minimize their exposure to abuse and arrest.<br><br>**Prisoners** have access to few services; confinement creates contradictions and challenges, e.g. in some places, NSP may be provided, but drug use is illegal and penalized; condoms may be provided but sex is prohibited. Comprehensive HIV prevention and harm reduction services and |

| COMMON VALUES / VIEWS / EXPERIENCES | COMMON PREFERENCES / RECOMMENDATIONS | ISSUES SPECIFIC TO INDIVIDUAL GROUPS, COUNTRIES or REGIONS |
|---|---|---|
| | | commodities should be available in prisons. |
| **7. Vulnerability due to lack of critical enablers in most settings.** | Community-based services can help to reach the most vulnerable in society, but action at the government/policy level is also needed.<br><br>***WHO requested to take a strong position on broader societal issues when engaging with countries at highest levels of government.*** | **YKP** experience more acute, age-related vulnerability due to lack of ID papers, exploitation from 'gatekeepers' and gangs, homelessness/lack of caregivers, blaming and shaming by families and in the education sector, poverty, mental health and lack of educational and employment opportunities.<br><br>**YMSMTG** experience violence, especially targeting young boys thought to be homosexual.<br><br>Especially in Eastern Europe & Central Asia (EECA), **PWID** are pushed to the edges of society, not considered as having families and friends, not considered worthy of health services, especially harm reduction.<br><br>In South Africa, **SW** who are marginalized or who work informally have little representation, creating challenges for advocacy and participation. |
| **8. Social / interpersonal issues:**<br>• Stigma and discrimination<br>• Family rejection<br>• Psychological distress<br>• Fear of disclosure | Social mobilization, public information and awareness campaigns to reduce stigma and discrimination against KP.<br><br>Peer support for practical information, self-esteem, validation of personal choices and identities. | **MSM** feel particularly affected by sexual and HIV-related stigma. |

## 3.2 HIV prevention: HTC, commodities and services

**Table 3. Values & preferences across key population groups: HIV prevention**

| COMMON VALUES / VIEWS / EXPERIENCES | COMMON PREFERENCES / RECOMMENDATIONS | ISSUES SPECIFIC TO INDIVIDUAL GROUPS, COUNTRIES or REGIONS |
|---|---|---|
| **1. Access to HTC services limited** by:<br>• Criminalization of KP behaviours<br>• Fear of harassment, detention, prosecution<br>• Targeting by police<br>• Lack of protection<br>• Societal fear and intolerance,<br>• Provider attitudes, harassment, coerced testing, lack of confidentiality, understanding, shaming of KP behaviours, poor communication skills<br>• Structural issues, cost, distance, separated services<br>• Individual issues such as HIV and sexual stigma, shame, self-stigmatization<br>• Poor quality of services (waiting times, stigmatizing signage, provider attitudes and skills) | Community-based, mobile and outreach services tailored to specific KP needs.<br><br>Integration of services; comprehensive services (HIV + other).<br><br>Safe spaces for all KP.<br><br>Legal reforms that recognize basic human rights and provide accountability and enforcement mechanisms.<br><br>Need to make providers more accountable for breaches of confidentiality, harassment and all other unprofessional and discriminatory treatment of patients. | **MSM** feel excluded by homophobia.<br><br>Age of consent is viewed as a barrier for most **YKP**, although many providers report making decisions about services in the best interest of young clients and waiving consent requirements when necessary. However, this can be risky for providers, and consent laws need to be reviewed where HIV prevention and treatment, sexual and reproductive health and harm reduction are concerned.<br><br>Free services most important for **YKP.**<br><br>Access enablers for **YKP** include outreach workers, peer educators, partners, brothels/pimps.<br><br>In MENA, **YPWID** face juvenile detention if they go for services.<br><br>In Vietnam, **PWID** required to attend testing with a peer educator in order to avoid fee; considered burdensome and a deterrent to seeking testing.<br><br>In Nepal, **YPWID** can be abducted with parental consent and forced into abusive and long-term 'rehabilitation programmes'.<br><br>**YKP** need opportunities to return to school or for skills development |