Key Populations and Power: People-Centered Social Innovation in Asian HIV Services

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Abstract

Key populations increasingly lead the design, implementation, and evaluation of HIV services. This increased power provides an opportunity to make HIV services more people-centered. Despite many challenges, there is a strong argument that key populations must play a greater role in HIV service planning, development, and delivery across the world. This viewpoint focuses on Asia where key populations have advocated for legal reform, engaged vulnerable groups to decrease stigma, co-created innovative HIV services, and developed new key population-led health services. We use a framework of people-centered social innovation to consider the increased power of key populations to control HIV service delivery. Greater power to key populations in HIV services is demonstrated in evidence from engagement programs, co-creation activities using crowdsourcing, and key population-led health services. Further research on key populations and their roles in HIV implementation and sustainable scale-up is needed in Asia and beyond.

Introduction

In contrast to an overall decline in HIV incidence among many groups, key populations still have a high HIV incidence and unmet HIV prevention needs.[1] Key populations include men who have sex with men (MSM), transgender people (TG), sex workers and their sexual partners, people who inject drugs, and incarcerated persons. Key populations are often marginalized in HIV responses in many Asian countries because of discriminatory laws, human rights violations, enduring stigma, and lack of appropriate care available in traditional service delivery approaches.

MSM accounted for 29% of new HIV infections in Asia in 2017.[2] HIV prevalence among MSM in Southeast Asia was the highest in Thailand (26·2%), Indonesia (25·8%), Malaysia (21·6%) and Vietnam (12·2%).[3] In China, 26% of new HIV infections occurred among MSM in 2014.[4] Additionally, a few countries in Asia still criminalized same-sex sexual behaviors between consenting male adults. Punitive laws and related health communication problems have contributed to a less than 60% consistent condom use among MSM in Pakistan, Laos, Sri Lanka, and Bangladesh.[5] Transgender people refer to all people whose gender identity differs from the sex they were assigned at birth. Among TG, available data indicate high HIV prevalence in many areas, including Jakarta, Indonesia (34%), Kuala Lumpur, Malaysia (23·9%), Cebu City, Philippines (11·8%)[6] and Bangkok, Thailand (13·8%).[7] At the community level, health communication materials frequently share insensitive messages which assume TG are a subset of MSM without recognizing the specific needs of people who identify as TG,[8] in health systems, healthcare providers can be insensitive to sexual orientation, gender identity and gender expression.[8] All of these problems can translate into poor access to health services and low levels of satisfaction from clients. The HIV testing uptake rate is low among TG in many Asian countries, including the Philippines (15%),

Pakistan (29%), Bangladesh (35%), China (34%) and Malaysia (43%).[7] Sex work is criminalized in 18 countries in Asia.[9] Due to legal constraints, it remains difficult for service providers to reach sex workers and their clients. This may translate into a missed opportunity for incorporating insights from sex workers into service delivery. A low proportion of consistent condom use was found among female sex workers (FSW) in Sri Lanka, Pakistan, and Vietnam, highlighting the unmet needs for HIV prevention among FSW.[10] Exacerbating the epidemic is the lack of attention given to male sex workers, among whom HIV prevalence is even higher than their female counterparts in many Asian countries.[11]

Despite these challenges, key populations increasingly lead the design, implementation, and evaluation of HIV services in some settings. This increased power provides an opportunity to make HIV services more people-centered. While participation can contribute to the empowerment,[12,13] tokenistic engagement may inadvertently decrease power.[14] This viewpoint focuses on Asia where key populations have advocated for legal reform, engaged vulnerable groups to decrease stigma, co-created innovative health services, and developed novel key population-led health services. We selected and reviewed successful cases, consulted regional experts, and then developed a framework of people-centered social innovation to consider engagement programs, co-creation activities, and key population-led health services.

People-Centered Social Innovation in HIV Services

A people-centered approach respects peoples' dignity and the need to be respectfully treated and empowered to pursue good health and well-being.[15,16] Derived from those principles, we further define a people-centered approach in HIV services as encompassing three fundamental elements.

First, adopting a view to see persons as a whole, rather than mere bearers of disease or as a threat to public health. This calls for a holistic examination of key populations' needs, including not only HIV and STI care and services, but also mental health, general health, and social support in the context of their dynamic interaction with the broad legal, cultural and socio-political environments.[17] Second, a people-centered approach acknowledges key populations' perspectives, experience and knowledge. Individuals with a lived personal experience of the barriers in traditional HIV programs and the facilitators of new HIV programs have a unique opportunity to take ownership of these new HIV programs.[15,16,18] Thus, shifting from a disease-focused to a people-centered approach values the human experience alongside clinical evidence.[16] Last, in a people-centered approach, key populations are empowered through the collaborative effort, where key populations, healthcare workers, and caregivers all contribute to the process of prevention, diagnosis and treatment.[16] This contrasts the current practices in many settings where healthcare providers are the sole hegemonic authority of medical knowledge. Although people-centered approach in HIV programming shares similarities with community-based participatory research (CBPR) in its emphasis on partnership, collaboration and capacity building, the two also differ.[19] A people-centered approach applies to increasing HIV-related service access and uptake among communities, without necessarily bringing in outsider researchers.

Social innovation refers to innovative activities and services carried out by organizations or groups motivated by the goal of addressing the identified needs of a community or population.[20] Evidence is beginning to accumulate in the Asia where key population-centered social innovation has occurred and has already triggered promising changes in HIV programming. Extending from previous

frameworks and discussions around community participation,[21-23] this evidence in Asia suggests the need to systematically examine these phenomena and how they alter local power relationships.

We searched peer-reviewed literature and program reports related to key populations and their power in the design, development, and evaluation of HIV services in Asia. We then summarized our findings and presented typical cases to illustrate key populations' increased power through people-centered social innovation.

Key Populations and Power in HIV Response in Asia

The term power has been thoroughly studied across different domains of knowledge and using various theoretical lenses.[24-26] Power is operationally defined as the ability to exert control over personal or community matters, in this case, the design, development, and delivery of HIV services. Increasing participation within the framework of decision making (e.g., higher levels on Arnstein's ladder of citizen participation) may give way to greater control over HIV service delivery.[14] However, this is not always the case, as demonstrated in tokenistic participation inadvertently decreasing overall power in the control of HIV interventions.[27]

Greater power transferred to key populations in HIV services is demonstrated in evidence from engagement programs, co-creation activities, and key population-led health services. Engagement is defined as having key populations involved in health outreach or dissemination, but not developing the messages or leading health services. Co-creation moves one step beyond engagement and has key populations developing messages and intervention materials. Key population-led services move farther than co-creation because key populations themselves lead the HIV service. In the following

sections, we draw on successful examples from Asian settings to demonstrate those three ascending levels of involvement from key populations in the HIV response.

Engaging key populations in HIV response

Meaningful engagement of key populations in HIV services, research and programming has been pivotal and effective in many Asian settings. Key populations play important roles in outreach and mobilization among their community members who are at risk of HIV. In Thailand, the Tangerine Community Health Clinic works closely with TG social media influencers through online platforms to increase community literacy, to generate demand for HIV and related services, and to reduce internalized stigma among TG communities (See Box 1 for more details).

Cambodia, China, Malaysia, and Indonesia all have HIV testing programs that draw on key population staff, an acknowledgement of the potential power of key population engagement in attracting the most at-risk groups and delivering the most-needed services. In Cambodia, HIV testing services for people who inject drugs has been delivered partly through peer-led outreach.[28] In China, community based organizations(CBO)–clinic hybrid service delivery is supported by MSM CBOs in collaboration with local clinical service organizations to provide HIV and syphilis testing to MSM.[29] In Malaysia where same-sex relationships are illegal, a non-government organization (NGO) offered community-based voluntary HIV counseling and testing and has served more than 700 clients, among whom more than 58% disclosed same-sex sexual behaviors.[30] Similarly in Indonesia, community screening sites provided a complementary entry point to HIV services among MSM reluctant to seek HIV testing at government-run health facilities.[31] In summary, engaging key

populations in HIV interventions is able to bring services to the community and its members who are otherwise marginalized by discriminatory laws and norms. With accessible HIV services and resources at the community, individuals can exert increased control over their health.

In addition, engagement of key populations contributes to advocacy and policy formulation in Asia. Together with academia, healthcare providers, multi-lateral agencies and governmental sectors, representatives from TG communities and organizations in Asia participated in the development of a blueprint document aiming to improve TG clinical services in this region.[32] The blueprint document has served as a guide for trans health and human rights in the region and was endorsed for publication by the core partners, including the Asia Pacific Transgender Network, the World Health Organization, the United Nations Development Programme, and the United States Agency for International Development.[32] In developing the blueprint document, members from the TG communities representing sub-regions of Asia actively engaged in various workshops throughout a year and advocated for human rights-based services for TG in HIV services. With technical assistance from healthcare providers inside and outside Asia, TG community members spearheaded the write-up of the blueprint document in 2015, which was unique for a regional policy statement. Key population's engagement in policy formulation demonstrated control over the delivery of HIV services.

Box 1. Transgender Communities' Engagement in HIV Response: A Case from Thailand

The "Tangerine" Community Health Clinic, established in November 2015 at the Thai Red Cross AIDS Research Centre, is the first transgender health and well-being clinic in Asia, where gender-affirming hormone treatment, HIV and sexual health services are integrated as part of the comprehensive service package. Tangerine is primarily run by a trained and gender-sensitive healthcare team, where nine of the total ten staff members are transgender women (TGW). (see supplement 1 for more information on Tangerine clinic and its services).

Key population staff at the Tangerine community were all paid, full-time workers, who were empowered throughout the processes of job application, training, delivering services, and appraisal. They were formally hired and expected to delivery high-quality work.

Tangerine has monthly engaged transgender social media influencers to increase its HIV service uptake through the Tangerine Facebook page as the main online client recruitment platform. Transgender social media influencers who engaged in sex work conducted Facebook live sessions to educate their sex work communities on HIV testing and PrEP and successfully reached and recruited TGW sex workers. In addition, TGW beauty icons were able to reach out and identify young TGW and HIV first-time testers via Facebook live sessions about safe hormone use.

By the end of April 2019, there were 2,623 transgender clients receiving clinical services. Of those, 1,586 (60%) were reached by TGW social media influencers and 1,502 (95%) of those who were reached received HIV testing. Among this group, 390 (26%) were first-time testers. A total of 93 (6%) TGW had a positive HIV test result. Tangerine also harnesses the power of online TGW communities to enhance offline healthcare services. It indicates that engaging TGW in HIV responses is effective in reaching marginalized groups, improving the uptake of HIV testing, and facilitating linkage to HIV prevention and care.

Co-creation of innovative HIV programs through crowdsourcing

Co-creation solicits innovative ideas form the 'bottom-up', as contrasted with traditional HIV services which are designed 'top-down' by policymakers. Co-creation not only facilitates that the content of social innovation reflects the lived, contextualized needs of key populations, but also empowers them to take ownership.[33]

Co-creation refers to a diverse group of individuals jointly producing a program for a mutually beneficial outcome (e.g., crowdsourcing). Crowdsourcing is one example of co-creation and is herein defined as having a group collectively solve a problem, either online or offline, and then

sharing the solution with the public.[34] Compared to traditional top-down approaches in creating HIV-related communication messages, crowdsourced approaches have been shown effective in generating culturally sensitive intervention messages.[34-36] In China, crowdsourcing has been used to co-create interventions to promote HIV testing among MSM communities and demonstrated a 40% increase in the probability of HIV testing over three months.[35] To co-create an HIV testing intervention, a 6-week nationwide open contest and a 3-day regional designathon (a hackathon-like event focusing on strategy development and material design) were organized to solicit images and intervention strategies around HIV testing tailored for MSM communities.[35] This crowdsourced intervention was appraised in comparison to traditional social marketing intervention through a stepped wedge cluster randomized controlled trial in eight cities in China (see Box 2 and Supplement 2 for examples of HIV intervention content created from crowdsourcing). The effectiveness of the crowdsourced intervention suggests the potential of crowdsourcing to co-create innovative and attractive HIV interventions. The co-creation process allowed key populations greater control in the development and design of HIV services.

In addition to its use in promoting HIV testing, crowdsourcing has also been employed to solicit ideas in creating condom promotion interventions and has demonstrated similar effectiveness in reducing condomless sex when compared to social marketing messages.[36] Crowdsourcing has been used to invite inputs from key populations about HIV cure research through an open contest soliciting ideas about what an HIV cure would mean to them as a person. This crowdsourcing activity provided an important voice about HIV cure research to key populations with lived experiences of HIV and HIV risk. Co-creating the meaning of HIV cure took the conversation beyond biomedical markers, viral loads, and reservoirs. Instead, it underscored the people-centered

approach to deepen the scientists' understanding of what it means to live with HIV.[37] A practical guide on crowdsourcing in health and health research has been publicized by the UNICEF/UNDP/World Bank/WHO Special Programme for Research and Training in Tropical Diseases to provide a guidance for using crowdsourcing in the context of health programs.[38]

Box 2. Crowdsourced HIV testing promotion messages created by MSM and for MSM in China

Crowdsourcing has been used in China and Thailand to solicit innovative ideas for designing culturally sensitive and effective health messages for HIV prevention and testing among MSM communities. Over the past five years, several crowdsourcing projects have been implemented by the SESH (Social Entrepreneurship to Spur Health) group in the forms of a designathon (where members from MSM communities design health messages and images for health promotion), an open contest (where contests were organized to elicit ideas openly from the public) and a hackathon (where diverse individuals create innovative technology platforms for MSM to better seek high-quality health care). One key lesson learned from the use of crowdsourcing in co-creating key population programs is to ensure that the results and the service product are shared with the community, thus closing the loop. Sharing the results could include the following activities: wide dissemination of messages through in-person and social media network; implementation of a program; organization of a pilot to evaluate efficacy; or other ways to share the finalist ideas with a broader community. Sharing typically includes both sending out these messages and telling the community how they were derived (i.e., through an iterative, community-led process).

Through co-creation, the vision of key population communities is translated into HIV services and their components. HIV related services co-created from crowdsourcing emerge from the community and demonstrate community's power to exert control over HIV service content and design.

Key population-led health services

Key populations also lead HIV-related health services in several Asian countries, including India, Thailand, and Vietnam. This approach has a key population responsible for managing, funding, designing, delivering, evaluating, and sustaining HIV services. Despite the complexity of implementing key population-led health services in certain aspects due to sociopolitical constraints,[39-41] population-led health services proved to be trusted and of high quality in several studies in Asia.[42,43]

In Thailand, trained lay providers who were members of MSM and TGW communities demonstrated their capacity to perform finger-prick blood collection and HIV rapid diagnostic testing with excellent accuracy compared to testing conducted by medical technologists. In 2016, 42% of all HIV tests among MSM and TGW in Thailand were implemented at CBOs.[43] HIV testing services provided by key population lay providers contributed to the diagnosis of 35% new HIV cases among MSM and TGW in the same year.[43] In addition, trained key population lay providers at these CBOs have dispensed pre-exposure prophylaxis (PrEP) to at least a quarter of all PrEP users in Thailand by the end of 2017.[44] Key population-led services in Thailand were largely driven by key populations who took control over types of services provided to their community and how those services were made available for the community. Services were focused on the comprehensive needs of key populations and decided by those who shared the lived experience. For example, services for male sex workers also included legal consultation and non-formal education sessions; services for transgender women included integrated feminizing hormone therapy; services were available in hotspot areas and during flexible service hours to suit living and working lifestyles; harm reduction services were added to the design based on lay providers' finding of increasing drug use among their clients. These are all bottom-up examples for key population-led health services.

In Vietnam, HIV testing led by key population lay providers increased the coverage and facilitated the effective diagnosis of HIV positive cases.[45] HIV testing interventions led by key population lay providers reached a large number of clients with an overall HIV positivity rate of 4·1%, almost three times higher than the estimated HIV positivity rate from facility-based testing during the same period (1·6% in 2016 and 1·5% in 2017).[45] Among the clients tested by the key population lay providers, most were first-timers; half of those who tested before had not tested in the last 12 months.[45] This suggests that key populations and others can play a larger role in directly delivering HIV-related services.

Similarly in India, HIV-related health services led by key populations including FSW, proved successful as shown in the Avahan project (see Box 3 for more details);[46,47] Sonagachi Project, led by FSW communities, demonstrated the collective power of key populations in the HIV response and stigma reduction through unionization and governance.[48,49]

Box 3. Key Population-Led Health Services and Key population Governance: Avahan in India

Avahan serves as a flagship program for key population-led health services in Asia focusing on HIV prevention for key populations including sex workers, MSM, transgender individuals, and people who inject drugs. Avahan exemplifies a comprehensive and complex large-scale project that expands across geographic areas (characterized by its coverage over six states). The projects were sustained for two terms of five years each, delivered combined interventions (ranging from community outreach, to clinical services) and were led and implemented by key population communities.

Within Avahan, the community mobilization was characterized by key population leadership. In 2004, social change agents including FSWs were identified as leaders. The social change agents led a series of services among their peers, such as advocating sex work as work, encouraging the organizing of CBOs striving for sex workers' well-being, and connecting sex workers to NGO-operated STI clinics. Avahan increased female sex worker collective identity, agency, and efficacy through enhancing the collective power of FSWs' leadership.

Challenges and Opportunities

The increased power of key populations was reflected in their engagement in, co-creation of, and leadership for effective HIV services across Asian countries (Table 1). The three levels of involvement may build upon one another. However, the capacity of key populations to champion HIV services relies on a pre-requisite enabling environment.[39] Decriminalization and protective laws to ensure key populations' human rights have been introduced in Thailand and some other Asian countries. Same-sex sexual relationships were decriminalized in India and same sex marriage was enshrined in legislation in Taiwan in 2019. Power is difficult to measure and can take various forms in different settings. A supportive legal and policy environment is essential for giving key populations greater power in organizing HIV services. This article draws on cases from settings where local governments and policies confer a certain level of support to allow demonstrable feasibility and effectiveness of key populations taking more control over the planning and delivery of HIV services. These trends cannot be generalized to settings with severe legal constraints, conservative cultural norms, oppression of civil society, and violation of the basic human rights of key populations. At the same time, the gradual expansion of enabling environments across Asia suggests that there will be more opportunities for key populations to co-create and lead health services in the future.

Second, sustainable financing is critically important for key population HIV services and participation. Increasingly, funding for HIV services in Asia is shifting from foreign aid to domestic funding.[50] To ensure sustained services and active participation of key populations, innovative financing schemes are needed to remove the persistent financial barriers to HIV service delivery.[51] Several different financial models for supporting key population HIV services have been developed,

including government, private, public-private, and social enterprise.[51,52] These and other innovative mechanisms can help ensure that these models are sustainable.

While empowering key populations is critical, advocacy and research should not be confined to key populations alone. Altering power relationships is often slow. The fact that in certain countries key population-led services have and are continuing to be accepted gives hope that further incremental change is possible. As illustrated in the three levels of this people-centered social innovation framework, key populations in selected settings of Asia are gaining increasing levels of control over time.

In this viewpoint, we used the term 'key populations' based on the World Health Organization definition. The definition is based on public health priorities and not necessarily the needs, desires, and experiences of people themselves. The successful delivery of people-centered social innovation in HIV care requires allies from across sectors, e.g. politicians, advocacy groups, the health system as well as families, friends, and supporters of key populations. Governments should review the laws and regulations to recognize the human rights of key populations and allow key populations to be at the forefront of the HIV responses. Commitment is needed to provide support and invest resources in the capacity building of key population leaders and service providers, in order to expand and support rapid scale up of the key population-led health services and promote sustainable community-driven HIV responses.

311 **Table 1. People-centered social innovation in HIV services driven by giving power to key**

312 **populations**

Conventional challenges	**Solutions**	**Actions addressed by giving power to key populations**
Service delivery	Engagement, co-creation and key population-led health services	• Utilize key population-led social media influencers to identify hard-to-reach populations at high risk • Apply a crowdsourcing strategy to co-create HIV preventive messages to increase condom use and HIV testing uptake • Train key population lay providers to perform certain clinical HIV services such as HIV counseling and testing, STI screening, PrEP and PEP dispensing, along with other demand-driven services such as gender affirming hormone services, legal services, and harm reduction
Policy and regulations	Engagement	• Review policy to support financial investment for and capacity building of key population-led health services across the HIV cascade • Advocate and participate equally with health professional institutions in revising regulations to allow key population to perform certain clinical HIV services according to task sharing strategies

Laws on stigma and discrimination	Engagement and co-creation	• Repeal laws criminalizing same-sex relationship, transgender identity and sex work • Organize public awareness raising campaigns to reduce stigma and discrimination towards key populations and HIV status • Introduce anti-discrimination laws for key populations and provide gender sensitization for health care providers to encourage an enabling environment in healthcare settings.

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Table 2. Indicators for power demonstrated in the three components

Component	Relation to power[§]	Public Health Indicators		Explanation
		Process-focused	Outcome-focused	
Engagement	Perceived personal control; Learned hopefulness	Content analysis that demonstrates that HIV-related messages and campaigns were effectively conveyed in social media	Testing and preventive services accessed, service coverage	Engaging in HIV response includes knowing status, increasing awareness, learning skills to protect oneself from diseases and illness which are manifestations of power as it demonstrates one's exerting control over one's own matters, in this case health.
Co-creation	Perceived community control; perceived efficacy for influencing the larger system	Key populations actively design HIV services, construct meanings, and create solutions	Control over the HIV intervention content and its implementation	Co-creation suggests power as it demonstrates the community's exerting control over the HIV program design and its content. Key population communities through co-creation are able to influence the larger system.
Governance/ KPLHS	Holding leadership positions at community organizations and activities	Key populations have opportunities and priority to lead HIV services and grow through capacity building and mentorship	HIV services are led by key populations themselves, who take control over the hiring process, finances, training, and service operation.	Key population have control over decision making and assume leadership roles, which demonstrates their control.

[§] Concepts adapted from the literature on control, power, and authority in public health.[27,53-55]

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Author Contributions

JDT conceptualized this manuscript. FY and RJ carried out literature review, acquired the data, and co-wrote the first draft of the manuscript with inputs from JDT, MB and NP. JDT, MB and NP provided critical revisions and essential references. All authors read and approved the final version that was submitted.

Declarations of Interest

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Supplement 1. Tangerine community health clinic:

https://www.youtube.com/watch?v=8KjCjLGau18

Supplement 2. HIV testing promotion video developed through a co-creation approach:

https://youtu.be/WbDpNrV3avg