

Frequently Asked Questions (FAQs)

Equity in antiretroviral treatment (ART) access for marginalized groups in India (FSWs, IDUs, MSM and Hijras/transgender women)

To accompany the document:

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First author's note: These questions were asked during my informal interactions with policymakers and program managers of government, UN-Indian agencies, and voluntary organizations. Hence, I have compiled the questions here. I have used the original wording of the questions – to retain the original conversational flavor.

1. When you talk about ‘equity in ART access to marginalized groups’, are you prioritizing certain groups over others? All PLHIV have equal rights to ART access – then why should some special status be given to certain groups?

Equal opportunity to ART access for PLHIV belonging to any subgroup is a premise of ‘equity’. Because these marginalized groups are particularly vulnerable in terms of becoming infected with HIV as well as in general, and because they face barriers to accessing healthcare services, the study was focused on these groups. That is, the overall context of existence of these marginalized groups is one that places them at a disadvantage. Equity in access in no way implies that these marginalized groups require privileged or ‘special status’ over other groups such as women and children in relation to ART access; however, additional barriers they face place them at a relative disadvantage. ***Indeed, barriers to ART access for all subgroups of PLHIV need to be identified and removed.*** For some groups, to ensure equal opportunity in ART access, additional interventions are needed, which is compatible with the framework of equity and is an obligation on the part of the government to ensure equity in health among various groups. These additional interventions to remove barriers to ART access are necessary components of basic equity and should not be viewed as giving special privilege/status to some groups over others. Rather, they are aimed at removing existing barriers in order to advance equity.

2. You listed barriers at several levels (individual, social and healthcare system). Among these, which ones need to be addressed first? Can you rank these barriers for policymakers to prioritize their actions?

In this qualitative study, our objective was to explore and understand various barriers to ART access for various marginalized groups. We have found many of these barriers are strongly interconnected. ***Thus, we need to address a range of barriers at various levels.*** But ***some barriers*** – healthcare system (including the program level), and social barriers – ***are more amenable to policy solutions*** and thus should be considered by policymakers and national HIV program managers. For programmatic purposes, opportunities to incorporate activities in existing programs to address the barriers at all levels should be considered as we have given in the list of recommendations. While some authors recommend introducing surveys in which one can ask people to rate/rank the barriers, such a ranking is more likely to focus on the individual level since individual level barriers are more likely to be perceived as important although key barriers exist at the policy level that may be more difficult for individuals to identify. For example, current drug users may rate homelessness as the top barrier to ART access from their perspective; nevertheless, government policy (implicit or explicit) that denies ART to current drug users may be a more pressing barrier to ART access for current drug users. Thus, there is also a need to develop tools to determine the relative importance of barriers but resource scarcity should not be the reason or justification for not taking actions to remove the barriers.

3. Do we need to focus on removing barriers to ART access for only some subgroups among these marginalized groups?

Our study was conducted among some subgroups among these marginalized groups. For example, MSM – kothi-identified men; FSWs – ‘home-based’ and ‘street-based’ sex workers. While these

subgroups are indeed found to face barriers, other subgroups (brothel-based FSWs, gay- and bisexual-identified MSM) might also face barriers and it is important to identify and address barriers faced by those subgroups as well.

4. You talked about barriers to ART access for marginalized groups. But where is the quantitative data to show that marginalized groups living with HIV are not getting ART from government ART centres?

Being a qualitative study, our study captured that which makes it difficult for marginalized groups living with HIV in accessing ART from government ART centres i.e., 'Why' they face barriers, and what needs to be done to improve the situation. The focus of the study was not to find out how many PLHIV among those who receive ART from the government ART centres are from marginalized groups. Our intent was not to document that government ART centres are denying access to marginalized groups. The issue of barriers to ART access runs much deeper and is more complex than mere denial of services. The ultimate goal of our study is to facilitate an understanding of why marginalized groups may not be accessing services, so policy and program decisions can be made based on this information. NACO releases data on the number of Hijras who receive ART from these centres (128 Hijras receiving ART at the national level at the end of August 2007) but no data has been released about other marginalized groups. However, qualitative data from other reports (INP/ITPC) and data from MSF-Mumbai corroborate our results that show PLHIV from marginalized groups in various parts of India face barriers to ART access. A study from Manipur reported that (in 2006) current IDUs constituted less than 5% of those accessing ART from the government ART centers in Manipur – whereas 49% of the reported AIDS cases were categorized as having contracted HIV through injection drug use (in 2006). (Sharma et al., 2007). (See policy brief – for more details). Thus, existing evidence supports our findings about barriers to accessing ART among various marginalized communities.

5. You mentioned that it is important to collect information about the 'marginalized group status' of PLHIV (disaggregated data) in government ART centers to find out what proportion of PLHIV getting ART from the government ART centres are from marginalized groups. But what about the confidentiality issues? What if others come to know about their marginalized group status?

It is important to maintain the confidentiality of the HIV-positive status as well as the marginalized group status of a person. But it does not mean that we should not ask for or record the marginalized group status of a person coming to ART centers or other government health settings. For provision of appropriate health care (e.g., appropriate counseling regarding safer sex for MSM/Hijras; connecting IDUs with drug/alcohol dependence treatment programme) it is important that healthcare providers ask about the marginalized group status of PLHIV in a sensitive and nonjudgmental manner. Same level of confidentiality in maintaining the HIV status of PLHIV should be taken in maintaining the confidentiality of the marginalized group status. Also, documentation about marginalized group status may also help us to find out the proportion of PLHIV from marginalized groups who are getting ART from government ART centers - though we may not want to rely upon only data from this source to monitor equity.

6. Many PLHIV from marginalized groups do not reveal their marginalized group status to the healthcare providers. So it is possible that adequate number of marginalized groups living with HIV are actually getting ART from the government ART centres but we do not have that information since they would be then considered as 'mainstream' according to the medical records. Since they do not reveal their being MSM or IDUs, health care providers should not be blamed.

Fear of discrimination (or having faced discrimination) might lead PLHIV from marginalized groups such as MSM, IDUs and FSWs to conceal their marginalized group status from their health care providers. Thus it is important that to build mutual trust between these communities and health care providers. If current drug users are denied ART by doctors when they are otherwise eligible, then current users might want to conceal their current drug use from their health care providers. Thus, for facilitating PLHIV to be open about their marginalized group status, health care providers need to be non-discriminatory and build trust with these communities. If these communities are not discriminated or provided substandard treatment even if they reveal their marginalized group status, then over a period of time it is likely that they will voluntarily reveal their marginalized group status. Also, as

mentioned in our previous response, we should not rely only on records from the government ART centers to monitor equity in ART access. (Also see response to the question number-4)

7. What could be appropriate monitoring mechanisms to ensure that marginalized groups living with HIV have equitable access to ART from government ART centers?

Using the routinely available data from government ART centres may not capture the marginalized group status of PLHIV unless the health care providers are trained adequately in sensitive history taking among PLHIV to find out their marginalized group status. Nevertheless, such routine official program data might still be useful for monitoring at least some 'visible' marginalized groups such as Hijras where marginalized group status is usually identified. But, one can think about conducting cross-sectional surveys among marginalized groups living with HIV to find out how many of those who are eligible for ART are not accessing ART. The reasons behind not accessing ART in spite of being eligible can be found out by qualitative methods. Thus, mixed methods studies conducted periodically (for example, every year) could be appropriate to monitor the equity in ART access. Such a study could comprehensively address other characteristics such as income level, marital status, urban/rural residence, etc., to find out inequalities due to other factors.

8. One of your recommendations states the need for a policy and action plan to ensure equity in ART access for marginalized groups. But, as you yourself have mentioned, NACO clearly says in NACP-3 plan, "ART need to be given for all who need it". So there is already a policy on equity.

It is commendable that NACO has this statement in NACP-3. It can be seen as an "implicit policy intent" in favor of equity in ART access. However, when the recommendation mentions "need for a policy and action plan to ensure equity in ART access" it refers to the need for an explicit policy that articulates equity in ART access for marginalized groups such as FSWs, MSM/Hijras and IDUs (and other disadvantaged populations) and lists the strategies that will be taken to achieve equity. The NACP-3 plan is silent about these strategies. Hence that recommendation was proposed, but not implemented. WHO (2004) has prepared a document that includes information about how to ensure equitable access to ART to marginalized groups, including sex workers, MSM and IDUs. Our government can prepare a policy and action plan based on that guidance document. (WHO. 2004. Guidance on ethics and equitable access to HIV treatment and care. Geneva.)

9. You listed barriers at several levels. There are barriers at the individual level too. Hence they are to be blamed for their problem in not accessing ART though it is open for everyone. That is, there is equal opportunity had they come to ART centres. No one is blocking them. So where is the inequity? And what can the government or health care providers do?

As we have mentioned in the reports/brief, many of the individual barriers are strongly connected to barriers at other levels – health care system, social and policy barriers. Though the ART program is theoretically open to anyone on a 'first come and first served' basis, marginalized groups face several specific constraints over and above the constraints faced by mainstream PLHIV in accessing ART centres. Thus, they are systematically less likely to be among those 'first served'. These population-specific constraints or barriers need to be removed to be able to say that these groups have equal opportunity in accessing ART from government ART centres. ***It is the responsibility of the government to identify and remove these barriers in order to ensure equity in ART access.*** Additionally, treatment is closely linked to prevention; by not addressing this critical issue a disservice is being done to broader efforts to control HIV infection rates. Healthcare providers can play an important role in being nondiscriminatory, not denying or delaying ART for eligible PLHIV from the marginalized groups, and linking the marginalized groups living with HIV to other necessary services.

10. NACO intends to provide first-line ART to 300000 PLHIV (adults) at the end of 2012. Do we need specific targets to be set for PLHIV from marginalized groups within this 300000?

Setting specific targets seems to be a good idea to formalize commitments. Any such target setting needs to occur at the local level. Depending upon the local epidemiology (in a particular geographical area) such targets can be set. For example, it may not be useful to say about 10% of the PLHIV among the 300000 PLHIV to be given ART by 2012 should be IDUs. IDU populations differ greatly in various states and districts. Hence, depending upon the size estimation and HIV prevalence of IDUs in a locality (say, district), local targets can be meaningfully set.