28th September 2010

Mr. K. Chandramouli
Secretary and Director General,
National AIDS Control Organisation,
6th Floor, Chandralok Building,
36, Janpath,
New Delhi 110003

Dear Sir,

Re: Concern over 'anti-rights' practices in interventions with most at risk populations

We write to you to express concern over recent practices introduced by the National AIDS Control Organisation (NACO) on Targeted Interventions (TIs) for most at risk populations (MARPs) namely, sex workers, men having sex with men (MSM) and people who inject drugs that infringe individual autonomy and confidentiality and also threaten the success of the National AIDS Control Programme (NACP).

I. **Prescription of targets for HIV testing of MARPs enrolled in TIs**

It has come to our knowledge that NACO has begun to follow a practice of target based HIV testing for MARPs, the achievement of which is linked to performance evaluation and future funding of the TI. While we recognise the importance of scaling up voluntary counselling and testing for HIV as well as the need for sound monitoring of the programme, it is our concern that where imposed as a target, HIV testing will take on an *involuntary* character, undermining the reach and effectiveness of the TI. Target based testing of MARPs has reportedly led to the following:

a. **Undue pressure on organisations implementing TIs:** Organisations implementing TIs have confirmed that the inability to meet testing targets leads to a negative evaluation by the Technical Surveillance Unit (TSU) and/or State AIDS Control Society (SACS), triggering a series of adverse consequences. These include downgrading of performance rating, reduction in the size of population to be served under subsequent grants, decline in funding and even disqualification from running TIs. This despite the fact that the TI may be performing well on other indicators such as – coverage through outreach, referral to STI screening and delivery of condoms or sterile needles.

   As a result, organizations operating TIs are reportedly resorting to coercive or compulsive methods to test MARPs in order to meet the prescribed targets. In some places, access to services provided by the TI has been made conditional upon

undergoing HIV testing. Some projects are reportedly submitting inaccurate reports by entering one person's HIV test result multiple times in the data base. Still others are reportedly organising 'health camps' to test persons with no reported high risk behaviour in order to fill in numbers of people tested for HIV. The priority of the intervention has evidently shifted from reducing HIV risks to increasing HIV testing.

Target driven testing encourages breach of rights of MARPs. Cuts in TI budgets for non-compliance with HIV testing targets diminish the strength and scale of prevention services for MARPs. Incorrect reporting and false data ultimately weakens the epidemiological vigour of the NACP.

b. **Undue pressure on peers and outreach workers:** Outreach workers and peer educators are the backbone of TIs as they are the first, and often, the only point of contact between MARPs and HIV related services. The burden of fulfilling testing targets has invariably fallen on them. Fear of a cut in salary, loss of work and a negative performance assessment has reportedly resulted in peer staff pressurizing their contacts to get tested. Some peer educators, for example, have reported falling at the feet of their contacts or paying money to gain acquiescence for HIV testing. Though this may not amount to coercion, such methods vitiate consent to testing. Further, they are likely to create mistrust and unprofessionalism in programme delivery.

c. **Impact on MARPs:** The success of TIs lies in their ability to reach out to MARPs in a non-judgmental and affirmative manner and instill confidence in the community. This is done through practices that respect rights and dignity of clients at all times. NACP-III Operational Guidelines for TIs clearly require services to be delivered in a caring and welcoming environment. Any compulsion to get tested can lead MARPs to lose trust in service providers and feel alienated from services. Recently, drug users from North-East India strongly condemned a move to have 100% testing of target population annually, deeming it an attempt to make them "guinea pigs". [1] It is well known that MARPs are least likely to access health services if they are deemed coercive or unfriendly.[2] The pressure to test for HIV is likely to drive MARPs away from TIs and other critical services.

d. **Bad public health strategy:** Given the concentrated nature of the HIV epidemic, India can ill-afford to weaken or undermine interventions for MARPs. Further still, the testing target imposed on TIs is unlinked to treatment and care for affected persons. It is

[1] Move on Mandatory Testing Questioned, Eastern Mirror, 2 June 2010, available at: http://www.easternmirrornagaland.com/index.php?option=com_content&view=article&id=24398%3Amove-on-mandatory-hiv-testing-questioned&Itemid=82

[2] UNAIDS, *A Framework for Monitoring and Evaluating HIV Prevention Programmes for Most-At-Risk Populations*, (2008), p. 23.

important that we do not begin to carry out testing for testing sake. Testing to report, for example, that 80% of sex workers have undergone HIV screening does not in itself serve any purpose. On the other hand, access to and use of condoms by sex workers or MSM is a better indicator of the programme's success. For MARPs, the rationale for pursuing aggressive testing without assuring access to anti-retroviral treatment is indeed questionable.

Target driven involuntary testing is a marked departure from the rights based approach followed under the NACP over the last two decades. It is inconsistent with NACO's successive policies on HIV testing including the National HIV Testing Policy, 1995, Guidelines for Voluntary Counselling and Testing, 2004 and Operational Guidelines for Integrated Counselling and Testing Centres, 2007 – all of which require HIV testing to be conducted with express, voluntary and informed consent of the client. These policies incorporate legal norms on patient's consent espoused by Courts in India[3] and abroad.[4] NACO must respect law and policy standards both in letter and in spirit.

II. **Line listing of MARPs under the TIs**

Project staff in TIs are mandated to record the name, address and other contact information of MARPs and share this data with TSU/SACS. The practice is ostensibly to improve follow up as well as monitoring of the TI, at the cost of client confidentiality. Unauthorised disclosure of personal information is illegal, unless required by law[5] or directed by Court in larger public interest.[6]

We would like to reiterate that respecting client confidentiality is not only a legal requirement but also a good public health strategy, as it improves attendance at clinics, enables clients' to reveal medical or related risks and facilitates correct diagnosis and treatment. Safeguarding privacy and confidentiality assumes greater importance for MARPs on account of the stigma and criminality associated with sex work and drug use. Organisations have confirmed that disclosure of personal information for line listing is causing many clients, especially MSM to drop out of TIs. This is indeed worrisome.

III. **Need for an Enabling Environment**

Instead of enforcing targets on MARPs, NACO must focus on the creating an enabling environment for HIV prevention and control. This would include *inter alia*:

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[3] *Samira Kohli v. Dr Prabha Manchanda* (2008) 2 SCC 1.
[4] *Reibl v. Hughes, [1977] 78 D.L.R 35 (Ontario High Court of Justice).*
[5] *Hunter v. Mann,* (1974) 2 All ER 414 QBD.
[6] *Mr X v. Hospital Z* (2003) 1 SCC 500.

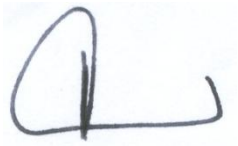
(a) **<u>Removing factors that discourage testing</u>**: There are many reasons that inhibit MARPs from seeking HIV counselling and testing. These include low self esteem, fear of loss of support from family/peers, loss of earnings especially for female and transgender sex workers, fear of incrimination for illicit sex/drug use, inflexibility of ICTC timings and insensitivity of counsellors. [7] A genuine uptake of voluntary HIV counselling and testing by MARPs is possible only if individual and institutional barriers to testing are addressed.

(b) **<u>Promoting measures that encourage testing</u>**: People seek test when the benefits of getting tested outweigh the potential risks of undergoing testing. Maintenance of confidentiality, protection against HIV related discrimination, ensuring free and timely treatment, removal of punitive laws are some of the means by which MARPs will come into the fold of HIV prevention and care. It is imperative that NACO pursue such strategies in earnest.

We understand that it has not been the intention of NACO to introduce mandatory testing or breach confidentiality. Yet, target based testing and line listing of MARPs, is inadvertently diminishing our ability to reach out and protect the most vulnerable members of society. It is also eroding the soundness and efficiency of our carefully designed AIDS prevention strategy. We therefore request you to convene a meeting with civil society and community groups to address the concerns raised.

Thanking you,

Yours sincerely,



Bharti Dey National Network of Sex Workers	Ashok Row Kavi Indian Network for Sexual Minorities	Luke Samson Indian Harm Reduction Network	Anand Grover Lawyers Collective HIV/AIDS Unit

[7] Chakrapani et al, 'HIV Testing Barriers and Facilitators among Populations at-risk in Chennai, India', INP+ (2008), p 12.