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HIV and Contact Tracing

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AIDS ACTION NOW! is a community-based group fighting for improved treatment, care and support for people living with HIV/AIDS (PHAs).

The Issue

There has been a rapid increase of newly identified cases of HIV infection arising from injection drug use (IDU) in major cities.[1] This is a crucial problem for one of the most vulnerable sectors of Canadian society, with the potential to get much worse. It points to the vital need for targeted prevention, support and treatment programs and for greater allocation of resources to community-based groups and programs that can effectively deliver these programs.

What this situation does not need is panic. But unfortunately, there is some discussion of returning to traditional public health measures of mandatory contact tracing and notification of partners of IDUs. This short-sighted response would be a disaster: contact tracing and other coercive measures have not worked for HIV prevention and they certainly won't work in the particular communities and cultures of IDUs: this hugely labour-intensive process will divert scarce resources from community-based preventative and education programs that we know do work; and fear of draconian measures will drive the most vulnerable people away from the support and education services they desperately need.

Public Health and Prevention HIV Infection: What Have We Learned?

Mandatory reporting of people with certain infectious diseases and contact tracing by public health authorities to notify partners or others that they may have been exposed to a communicable disease have long been part of the traditional public health repertoire.[2] Contact tracing has been widely applied in strategies to prevent sexually transmitted diseases. The most effective notification strategies have been voluntary, with the infected people themselves or their doctors contacting former partners, but contact tracing can also be compulsory. Coercive intervention has tended to be applied to highly infectious

diseases where people can be effectively treated so that they are no longer infectious; identification and treatment of people with tuberculosis is the most prominent example.

The overall record of direct public health intervention has been mixed. Experts generally see that broader education, rising social and economic standards, and overall health and health care improvements have been more important than the deployment of coercive measures such as mandatory contact tracing in bringing infectious diseases under control. There has also been real concern that coercive powers have historically been felt most sharply by the more vulnerable and marginalized sectors of society - when STDs were seen as a crisis, prostitutes were rounded up, not their clients; when tuberculosis was seen as a crisis; it was poorer people who tended to be quarantined. Most importantly, there is a crucial difference between diseases for which mandatory contact tracing has been used and HIV; finding people who are infected meant that they could be treated and cured, so that they are no longer infectious. While promising new treatments are finally emerging, HIV disease is not yet curable and people remain infectious for their lifetime. [3] In addition, HIV generally progresses more slowly than most other diseases which are subject to traditional public health measures.

There has now been over a decade of experience with public health and community-based campaigns to prevent the spread of HIV infection and we can draw some key lessons on what has worked. [4] The most effective prevention campaigns have been:

- developed by community groups - using straight-forward, user-friendly messages;
- targeted to particular communities, cultures or other social groups;
- delivered by groups based in those communities; and
- based upon health promotion , individual empowerment and harm reduction models.

What is the public health role in all of this? The best public health, education and other government agencies' campaigns have generally involved extensive consultation and partnerships with community-based groups, and have been based on similar fundamental values of health promotion and empowerment. Within considerable and continuing debate, a voluntarist consensus has emerged that traditional public health activities of contact tracing, notification and monitoring can only succeed with the co-operation and participation of infected people.

None of this has been easy. Human behaviour is incredibly complex and there is much we do not know about influencing change in intimate areas of social life. Continued worrying levels of new infection among young gay men, women and IDUs show that significant challenges remain in ending the AIDS epidemic.

Coercive Public Health Measures Don't Work

This section highlights why compulsory contact tracing has not worked in the HIV epidemic.

Needs Cooperation

Whatever the statutory requirements and whatever the legal powers Medical Officers of Health have at their disposal, partner notification ultimately cannot work without the cooperation of the HIV+ person. People cannot be forced to remember their past contacts and name them; they can simply lie and no amount of pressure from public health authorities can produce reliable results. This logical and fundamental point was emphasized in the comprehensive 1992 report from the Ontario Law Reform Commission on HIV testing.

Labour Intensive

Even if partner notification is voluntary and PHAs are committed to trying to find former partners, there can still be significant practical difficulties. It can be virtually impossible to identify and trace all contacts -- memory fails, people move--and involving public health in large-scale contact tracing is incredibly labour-intensive.

Partner notification, developed in earlier periods for different diseases, is also limited by the particular natural history of HIV infection. People with HIV/AIDS remain infectious throughout their lifetimes; would partners have to be notified not just when a person first comes to the attention of public health authorities, but from then on? Does this mean lifetime compulsory monitoring and surveillance of PHAs' partners to ensure safer sex and needle use is being practised? It is sociologically improbable that public health authorities could insert themselves into people's intimate lives for so long. It is economically inconceivable that the resources needed for lifelong surveillance could be found in this era of fiscal restraint. A far better strategy, of course, is to concentrate resources on prevention education so that all, infected and HIV-alike, are empowered to practise safer sex and needle use.

Diverts Scarce Resources
These practical difficulties point to the broader cost of coercive public health measures. Expensive and labour-intensive contact tracing will inevitably divert scarce resources from more productive and effective community-based prevention education campaigns.

Inconsistent Practice
There has been tremendous variation in attitudes and practices among different Medical Officers of Health (MOHs) in relation to using their coercive powers. For example, as anonymous HIV testing was being debated and implemented in Ontario, a major area of concern was that a disproportionate number of Section 22 orders had been issued by one MOH. There is no reason to expect that there would not also be significant inconsistency in MOHs' use of their coercive powers to try to identify and trace partners.

Drives People Away
Public health experts and community advocates have long argued that coercive measures drive people away from the public health system. The context for this concern was, and remains, pervasive discrimination against PHAs and stigmatization of AIDS and those infected. Many people with HIV wanted to keep their status secret to avoid this stigmatization. Compulsory contact tracing becomes a barrier when people fear that their positive status could become known as authorities tracked down their former partners.

Compulsory reporting and contact tracing can also drag doctors into, in effect, a `policing` role. This in turn creates incentives for PHAs to be dishonest with their doctors, weakening the doctor-patient relationship and effective treatment management.

The most effective prevention campaigns have been based on cooperation between various public health and community-based groups and a climate of mutual confidence and trust. [5] Public health coercion undermines this climate.

The Underlying Message
The underlying assumption of compulsory contact tracing and other coercive measures is at best paternalistic, that people cannot take care of themselves; at worst, it assumes that people cannot be counted on to behave responsibly. Not only are these assumptions unfounded and objectionable, they are distinctly dangerous. The implication that public health authorities will somehow protect the `general public` from dangerous infected people undermines the fundamental message of effective safer sex and needle use campaigns-- that everyone should protect themselves all the time.

Given all of this - that coercive contact tracing is ineffective for HIV, that it may do more harm overall than good -- one might wonder how there can still be any support for coercive public health measures? The answer is that these measures are largely symbolic - they are not about achieving measurable prevention and education outcomes, they are about looking like something decisive is being done.

Coercion is Even Less Effective for IDUs

The purely symbolic nature of public health coercion is even clearer in demands for contact tracing to stem the spread of infection among IDUs. All of the reasons coercive public health intervention has not worked and cannot work to prevent the spread of HIV infection are much more pronounced for IDUs.[6]

More Difficult in Practice

Identifying, tracing and notifying partners will be virtually impossible. Given the realties of drug use, remembering contacts will be unreliable. It will then be extremely difficult to find people who have been identified as possible partners. Drug users tend to be a more marginalized, largely underground and mobile population. And, of course, drug use is illegal. These challenges are even greater when considering the long-term monitoring and surveillance implied by lifelong partner notification.

We noted above that there has been considerable inconsistency among Medical Officers of Health in how they have used their coercive powers. There is no reason to expect that this kind of variability would be any less pronounced for IDUs. There is certainly some anecdotal evidence in the community that MOHs have been threatening or using Section 22 orders against IDUs in an arbitrary manner.

As with other PHAs, voluntary cooperation is crucial to any partner notification strategies, whatever MOHs' formal powers. That vital methadone, treatment and support services are largely unavailable to most IDUs, and that they are obviously not a priority for public health authorities, is hardly an incentive for IDUs to cooperate.

Even More Labour Intensive

The staff and administrative resources needed to undertake contact tracing will, as a result, be even more enormous for IDUs. At a time when community-based preventive efforts and needle exchanges are starved for funds or unavailable to so many, this would be a criminal misuse of scarce resources.

Stronger Fear of Being Identified

Drug users' reasons to fear public health authorities and loss of confidentiality are much stronger than other PHAs. The discrimination and prejudices associated with AIDS are compounded by equally harsh societal stigmas and harsh legal sanctions surrounding illicit drug use. The fear of being publicly identified as HIV+ and as a drug user or of having one's former partners and friends identified is an enormous barrier. Offering up names of former partners for contact tracing will be seen as no different than informing.

Drive HIV+ IDUs Underground

The consequences of compulsory contact tracing will be disastrous. The fear of being identified as HIV+ and a drug user, and of having former contacts identified and traced, will drive IDUs even further underground. IDUs on the street will not make neat distinctions between public health authorities, who are responsible for coercive contact tracing, and other public agencies and health care practitioners that provide vital services. Mistrust and fear of public health coercion may very well drive IDUs away from all publicly funded institutions (e.g. hospitals or doctors that are required to report cases of HIV) and community-based service providers.

Users will avoid testing or treatment until they are really sick and this delay and avoidance will occur at a time when the prognosis of HIV treatment is finally getting so much better. To support policies that drive IDUs away from this potential of longer life and improved health is unethical and inexcusable.

Women

Proportionately more HIV+ IDUs are women and contact tracing poses particular difficulties for them. [7] Women are vulnerable to violence and abuse from current or former partners who have been identified and traced by public health authorities because of them. And women are vulnerable to abuse and desertion when current partners learn that the women are HIV+.

More generally, public health campaigns have often failed to address power imbalances in a male dominated society; it has long been recognized that women face far greater difficulties negotiating safer sex and needle use. To blithely call for coercive contact tracing without considering the impact on women continues this irresponsibility.

Even Worse Message

Demands for coercive public health contact tracing play into prevailing hysteria about drugs and drug users as a pool of infection, threatening to leak out into the general public unless bold action is taken. The issue is doubly perfect for opportunists - look decisive in dealing with a public health crisis and look tough on drugs.

Just as ominously, use of coercive public health powers could also legitimate other "moral" judgements around drug use. For example, doctors are publicly questioning whether IDUs should be given access to protease inhibitors and other promising new drug combinations because they believe IDUs will not be able/willing to comply with the rigorous treatment regimens.

Most fundamentally, we must remember that the mandate of public health is to promote the health of the public, especially its most vulnerable members. It is hypocritical to call for coercive measures when treatment, care and support services for IDUs are so inadequate and inequitable. Recent research continues to show the importance of needle exchanges. A major comparative international review of 214 studies published in the Lancet demonstrated lower infection rates in cities with needle exchanges. [8] A more recent report from the Vancouver Injection Drug Use Study concluded that needle exchanges were not enough to curb infection on their own, but should be considered one component of comprehensive programs including counselling, support and education. [9] The importance of such programs is well researched, but adequate resources have not been directed to them. Similarly, specific HIV prevention campaigns for IDUs based in their communities and cultures can be effective, but there has not been enough investment in these programs. Finally, we know that IDUs need methadone and other treatment and support programs, but access is very limited.

What is needed

There must be no compulsory contact tracing of IDUs or anyone else. The `quick fix` of public health coercion cannot work.

There may be times when PHAs want to notify former partners - that is, for voluntary partner notification. And there may be times when PHAs will seek help from their health care providers, community organizations and even public health authorities to do so. These authorities must be prepared to assist PHAs in a sensitive, confidential and effective manner.

But voluntary contact tracing can only ever be a small part of broader public health prevention strategies; it must not divert scarce resources from targeted community-based efforts, the effectiveness of which has been demonstrated time and time again.

There must be a proactive responsibility on public health authorities to do all they can to get information and resources into individuals' hands so they can protect themselves from infection and to support the community-based organizations and programs that have delivered effective prevention education and health promotion so well. To consider expanding coercive measures when this responsibility has not been met is hypocritical, wasteful and dangerous.

Nowhere is this responsibility clearer than for drug users. Public health strategies for IDUs must include needle exchanges, community-based prevention programs, methadone and other treatment and support, and working to change the social and economic conditions that underlie addiction. There is no room for coercion.

1. Health Canada, Health Protection Branch, Epi Update (Ottawa: the Branch, Jan 1997)
2. For an overview of public health response to AIDS in the United States see Ronald Bayer, *Private Acts Social Consequences*: *AIDS and the Politics of Public Health* (New York, Free Press, 1991)
3. While there are strong indications that new antiretroviral drug combinations can reduce the virus in people's systems to undetectable levels, it is not yet clear how permanent this is and what implications it may have for infectiousness.
4. For a somewhat dated but comprehensive review of preventive programs see Ronald Valdiserri, *Preventing AIDS: The Design of Effective Programs* (New Brunswick: Reuters University Press, 1989)
5. Bayer, Private Acts, Social Consequences
6. For research on HIV prevention and services for IDUs, see the series cited above and particularly Nicholas Dorn, Sheila Henderson and Nigel South, eds, *AIDS: Women Drugs and Social Care* (London; Falmer Press, 1992)
7. Ibid and Lesley Doyal et al, eds.,*AIDS: Setting a Feminist Agenda* (London:Taylor & Francis, 1994)
8. In Vol 349, #9068; cited in Community AIDS Treatment Information Exchange "International study reveals success of needle exchange programs," retrieved from www.catie.ca 25.6.97.
9. Cited in Reuters Medical New, *"Needle Exchange Programs ALson Ineffective in Preventing HIV Spread";* see also reports of recent conferences that emphasized the importance of the early development of needle exchange s and community education and outreach "IV Drug-Related HIV Spread Contained by Outreach, Needle Exchange" (28May, 1996) and *"HIV Prevention for IV Drug Users: The impact of Needle Exchange Policies" (21 Feb., 1997)* all retrieved from www.reutershealth.com/news 25.6.97 and 3.7.97