

**MYTHS, MEANINGS, AND MEASUREMENT:  
ESTIMATING HIV PREVALENCE IN THE  
SOUTHERN CAUCASUS**

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## **Executive Summary**

This paper examines patterns in HIV screening in the southern Caucasus (1994-2006) to illustrate how epidemiologically knowledge is constructed within the constraints of local meanings and mythologies relating to disease. Using official testing data, legislation on testing, media reports and in depth interviews with National HIV/AIDS center staffs, IGO (International Governmental Organization) officials and epidemiologists in Armenia, Azerbaijan and Georgia, I analyze the cultural and contextual factors influencing testing coverage, sentinel studies and estimation. Social beliefs regarding HIV/AIDS influence information reception, risk perception, voluntary testing, mandatory testing and sentinel testing approaches. The wide variations in estimated HIV prevalence in the region, mandatory testing structure and lack of consensus regarding the number of individuals engaged in risk-related behavior continue to limit the generation of precise estimations through standard epidemiological techniques and estimation procedures, making the shift to evidence based assessment in the region contentious. Estimation modifications reflecting local conditions are discussed.

## **Introduction**

The ability to measure disease prevalence is inherently linked to the complex social and institutional settings in which individuals and organizations create meanings of health, develop perceptions of risk, and balance the costs and benefits stemming from identification of disease. Health mythologies play a central role in determining the development parameters of “disease discourses” for individuals, families, social groups, local and international public health organizations, and States. This is especially true in terms of stigmatized illnesses associated with the discrimination of those affected, such as HIV.

This paper examines patterns in HIV testing, surveillance, and estimation in the southern Caucasus (Armenia, Azerbaijan and Georgia) between 1994 and 2006, a region with large variances in estimated HIV prevalence and varying approaches to the analysis of HIV transmission patterns and prevalence estimation. I seek to illustrate how types of epidemiological knowledge, in the form of HIV transmission patterns and prevalence estimates, are constructed within the constraints of local meanings and mythologies relating to disease. Tracing the influence of local socio-historical context on patterns of voluntary testing, institutionalize surveillance patterns, and sentinel testing techniques sheds light on the ways local beliefs and perceptions influence ideas of health, risk and monitoring at the micro and macro level.

Increased attention to the means and methods of HIV testing, surveillance, and estimation are particularly critical as we enter the fourth wave of the pandemic. As, Barnett and Whiteside (2006) highlight, the urgency of interventions in the earlier years of HIV/AIDS emergence was driven by the fact that “people were dying” (Abantu Abaafa!). As we approach the second decade of the new millennium, people continue to die, preventable infections still occur, and concerns over emerging infections in “second wave” countries such as Ukraine, Russia and China loom.

However, the rapid adoption of interventions, advocacy of ever more dire predictions, and maintenance of urgency over cautious systematic analyses present formidable barriers to the effective use of well over two decades of accumulated intervention experience.

A lack of critical analyses of existing knowledge can also contribute to crisis fatigue among policy makers, heighten popular suspicion, and does precious little to facilitate the generation of solid public health infrastructure for overall infectious disease surveillance and monitoring. Present concerns and debates regarding HIV prevalence estimations, justify the additional study of precisely what is known regarding HIV prevalence and patterns of incidence, highlighting the importance of how knowledge concerning HIV is constructed within local contexts.

The recent downward revision of the number of people living with HIV/AIDS (PLWHA) in India from 5.7 million (the largest in the world) by more than half (to 2.5 million), provides clear evidence for caution in extrapolating data from antenatal clinics, and the superiority of broad based, representative population testing. (UNAIDS/WHO 2007; Dandona and Dandona 2007) A 16% decrease in the estimated number of people living with HIV/AIDS globally between 2006 and 2007, attributed in part, but not entirely to the Indian revisions, points to improvements in estimation techniques and data quality (UNAIDS/WHO 2007:3). Improved testing technology enables the inclusion of reliable HIV testing in population surveys such as the Demographic and Health Surveys. These survey based estimates have, for the most part, led to more markedly more modest overall estimations of HIV prevalence in Africa, than those generated through sentinel testing and antenatal clinics. (Vinod, et. al. 2006)<sup>1</sup>

Concurrent with improvements in testing technology and calls to reconsider heavy reliance upon antenatal clinic data for prevalence information, critiques of UNAIDS, are leveled by analysts

outside and (formerly) inside the institution. In a recent release, Helen Epstein (2007) argues that UNAIDS overplayed the HIV risk to the general population in Africa by under emphasizing the importance of broad simultaneous sexual networks for transmission. Recent survey results from India support charges that UNAIDS substantially overestimated the generalize risk in that country, and is often referred to in critiques of estimates for all of Asia. (Dandona and Dandona, 2007)

In a second recent volume book, epidemiologist James Chin, formerly with UNAIDS, strongly criticizes the standards estimation approaches and surveillance standards set by UNAIDS. In detailed analyses of advocated methods for sentinel testing, monitoring standards, and estimation techniques, Chin argues that UNAIDS systematically advocates strategies that knowingly overestimate prevalence, in order to highlight the importance of the organization's mission and the need for additional resources. (2007) Other HIV/AIDS scholars bristle at the claims of biased estimates, preferring to focus upon the difficulties associated with poor surveillance, precise estimates of groups at "risk", and the myriad challenges presented by the socially embedded nature of HIV risk to techniques of epidemiological estimation. Many HIV/AIDS advocates question the wisdom, and even the ethics, of advancing ideas that may potentially decrease the perceived global urgency for action or high priority of funding for HIV/AIDS related programs, when significant unmet need for education, testing, and treatment remains.

Heated debates concerning estimates of HIV prevalence and incidence are likely to continue, in both high and low prevalence setting. The underlying assumptions and modeling approaches embedded within standard projection packages such as Spectrum, UNAIDS advocated Epidemiological Projection Procedures and supporting approaches such as Workbook, will continue to be debated, adjusted, and improved, particularly as new data linked to large scale

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<sup>1</sup> Improved testing technology, enabling the identification of recent (180 days or less) and chronic infections, has been employed in the United States, leading to an *upwards* estimation of new HIV infections per year (incidence) from

testing through national surveys emerges. While attempts to standardize both data submission and estimation approaches seek to enhance comparability and quality<sup>2</sup>, universal approaches are unlikely to precisely reflect local cultural practices, risk behaviors or other aspects of local context. Related, the emergence of large scale survey-linked monitoring is unlikely to be feasible, acceptable, or efficient in all settings.

In many countries of the former Soviet Union, a region identified as within the “second wave” of the pandemic, the debates concerning estimation techniques may be premature. With the exception of Ukraine and Moldova, prevalence rates are low at present, although catastrophic prognoses have been forwarded, particularly for Russia. (Eberstadt 2002) The region is clearly challenged by low knowledge levels, high perceptions of stigma and wide spread misconceptions regarding transmission possibilities, treatment, and prevention. These trends contribute significantly to difficulties in monitoring and testing.

Discussions with participants in the second Commonwealth of Independent States Monitoring the AIDS Pandemic meeting in Moscow in June of 2007 highlighted problems with gathering the “raw data” used as a basis for the estimation techniques providing the focus of their training. The very low levels of voluntary testing, an absence of clear and reliable prevalence in core risk groups, continued debates concerning the size of population groups engaging in risk-related behavior, and problematic legislative context were all mentioned as barriers to the development of reliable base data for estimations. As one experienced epidemiologist from a National AIDS center in Central Asia commented:

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40,000 to 60,000 utilizing the STARHRS estimation method (See Brown 2007; Lee and McKenna 2007)

What does it all mean, if we start with rates empty of meaning? How many different types of prostitution are there? How many different groups of drug users? Prisons? MSMs (men who have sex with men)? The only groups we really monitor are pregnant women, and, thanks to god,<sup>3</sup> those numbers are low. We monitor new soldiers, but miss those who can avoid service. Still, those numbers are closed to us for national security reasons. (Sighs) So, once again we will follow standard approaches, generate these estimates and tell our leaders the number of cases is somewhere between 500 and 500,000, and they will tell us to come back when we know anything.

(Informal Interview, translated from Russian and cited with permission and verification, June 29, 2007)

Beginning with the assumption that “anything” we can know about HIV prevalence and incidence is constructed within the constraints of the meaning of disease and the social beliefs (regardless of their accuracy) associated with the illness, I use official testing data, legislation on testing, media reports and in depth interviews with National HIV/AIDS center staffs, IGO officials and epidemiologists in Armenia, Azerbaijan and Georgia, to analyze the cultural and contextual factors influencing testing coverage, sentinel studies and estimations of risk group size. Highlighting the importance of testing coverage, sentinel study practices and contextual influences can provide important background information on estimation procedures, critical for evaluating variation in prevalence, incidence, and transmission patterns.

The countries of the southern Caucasus, Armenia, Azerbaijan, and Georgia, share several Soviet era institutional and attitudinal legacies with other countries of the former Soviet Union. Each possesses an active National AIDS center, and officially registered cases are uniformly noted as significant underestimates of true prevalence. (Buckley, 2005) At present HIV prevalence is low and individuals diagnosed with AIDS are relatively rare; however each of the countries are

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<sup>2</sup> See for examples the new CRIS standards set forth by UNGASS.

<sup>3</sup> Though earlier she mentioned being a Muslim, at this phrase she crosses herself, a common performative gesture for older women in Russia.

struggling with massive temporary labor migration, significant numbers of intravenous drug users (IDUs), a growing commercial sex work industry, low knowledge levels concerning HIV/AIDS, and widespread poverty.

### **Goals and Guiding Questions**

Using the three countries of the southern Caucasus as my case studies, I examine five specific questions in this paper, in order to better understand the influences of social and institutional context on the generation of information on HIV. In doing so, I hope to contribute to our background understanding of issues linked to current global debates concerning HIV estimation techniques. Each of the following questions will be assessed in terms of variation over time, and across country.

- ❖ What are the general patterns of testing within the region? How do state regulations (legislation) and public perceptions of HIV influence testing coverage?
- ❖ How is the route of transmission attributed? How might the processes of attribution influence reported patterns of transmission?
- ❖ How consistent are the methods and findings of sentinel studies in the region?
- ❖ What are the approaches used to estimate the size of groups engaging in risk-related practices?

### **Setting and Case Selection**

There is, at present, unanimous agreement that the number of individuals living with HIV/AIDS is undercounted in the region, and that the actual and registered HIV prevalence in the region is likely to rise in the coming decade. Disagreement exists on the level of underestimation, leading to difficulties in comparisons, overall confusion, and increasing “crisis fatigue” among policy makers and citizens. Assessments in 2005 of social and cultural risk factors, sponsored by

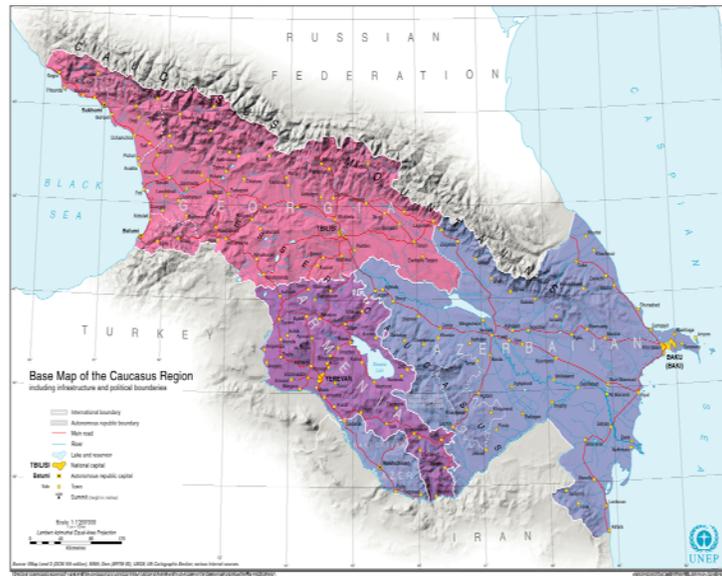
UNESCO, highlight variations in testing prevalence and targeting, finding that structural issues, cultural norms and poor information often deters voluntary testing among vulnerable groups, and mandatory testing tends to focus on low risk groups. (Popoyan, et. al.2005, Megerramov et. al. 2005, and Nijaradze et. al. 2005) As in other “second wave” countries, testing coverage is under assessed, estimates of HIV prevalence and shifts in transmission patterns differ widely, and the variation in estimates of the number of people living with HIV are subject to source agency concerns and biases.

The countries of the southern Caucasus (Armenia, Azerbaijan and Georgia) play an increasingly important role in global energy markets, international labor flows and efforts to combat global narcotic trafficking. Located between the Black and Caspian Seas and bordering Russia to the north and Turkey and Iran to the south, the region struggles with persistent poverty, socio-economic instability, collapsing public health systems, ethnic hostilities and significant concerns over the porous nature of their borders. (See Figure One) Economic and political developments such as the opening of the Baku-Tbilisi-Ceyhan oil pipeline in 2005 and Georgia’s “Rose Revolution” in 2004 supported optimistic global assessments of the region’s development possibilities.

More recently, continued concerns over political corruption, rising socio-economic inequality, continued strife over regional autonomy, limited tax collection capabilities and persistent inadequacies in social service provision have damped such positive views of the region. Political unrest in Georgia, violent clashes between the government and opposition in Armenia, and continued human rights concerns in Azerbaijan cloud hopes for stability in the region. The inclusion of Eurasia within the coming “second wave” countries in the HIV/AIDS pandemic, amplifies the challenges associated with regional institutional uncertainty. Competing priorities

stress the limited state capacities of Armenia, Azerbaijan and Georgia, impeding prevention efforts, limiting the ability to monitor the development of the pandemic, and amplifying the social, economic, and political threats raised by the spread of HIV/AIDS.

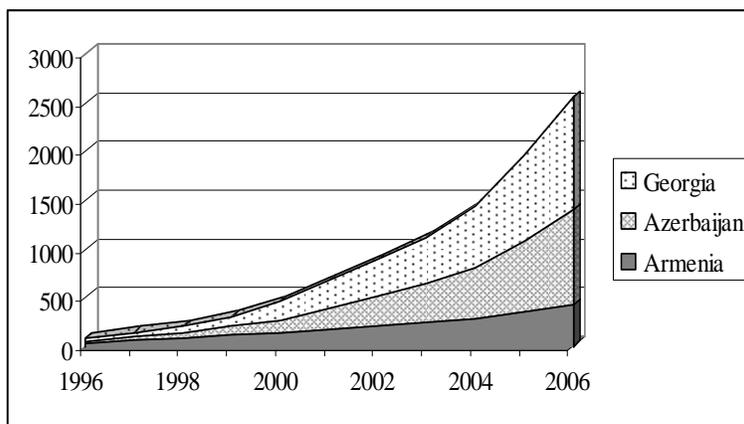
**Figure One. Map of the Southern Caucasus**



Officially registered HIV prevalence in the southern Caucasus remains low, but three trends in the data provide a source for alarm. Recent reported increases in reported cases are steep. Transmission modes appear to be shifting from primarily intravenous drug use to higher proportions of new cases attributed to sexual transmission. Related, the proportion of women among people living with HIV is growing, an issue often cited in intergovernmental agency (IGO) and non governmental agency (NGO) reports. At the end of 2006, the regional total of registered individuals living with HIV stood at 2,550, 30.5% of whom are classified as having acquired the virus through heterosexual contact. (See Figure Two). At the close of 2006, UNAIDS estimates the number of HIV-positive individuals in the region at 13,900 (5.45 times higher than official numbers). In Eurasia, women were rare among individuals registered with HIV infections in the 1990s (11% of all registered cases), but by the end of 2006 accounted for 28% of all cases, and

approximately 20% of all registered cases in the southern Caucasus.<sup>4</sup> While total HIV prevalence rates at present may appear modest, the recent rise of infections in Ukraine and the Russian Federation illustrates the rapidity with which HIV can spread within national populations.

**Figure Two. Cumulative Registered HIV Infections, southern Caucasus 1996-06**



Source: WHO/CISID <http://data.euro.who.int/cisid/?TabID=39145>

The southern Caucasus provides an interesting and important case study for the analysis of social influences on estimation construction. As is many countries with relatively low HIV prevalence, precise estimates are very difficult to generate. Individuals are often hindered from seeking testing by the highly stigmatized nature of HIV, low knowledge levels concerning treatment, and declining confidence in health services across the region. In the southern Caucasus, dire reports claim that actual prevalence exceeds registered prevalence by a factor of ten, or even higher. Sentinel testing in all three countries indicates significantly elevated rates of HIV infection among commercial sex workers and intravenous drug users. However, the methods and estimates these small scale non random investigations often vary, and are difficult to extrapolate. Results from blood donor screenings, particularly in Georgia (where paid donations are the norm) are a possible source from alarm. Over 35 of every 100,000 donations was HIV positive in 2004, a level

<sup>4</sup> Statistics in this section rely upon the 2006 EuroHIV Report, UNAIDS 2006 estimates, and the World Health Organization CSID data base.

in line with high prevalence regions such as Russia, Estonia and Moldova.<sup>5</sup>

Registered cases from antenatal clinics in Armenia, Azerbaijan and Georgia remain low, and local public health specialists concerned with issues of anemia, tuberculosis, heart disease, and other diseases with vastly higher prevalence rates increasingly question the high prioritization of HIV/AIDS related interventions, directing criticisms towards high end estimates of the total number of PLWHAs in the region.<sup>6</sup> The countries of the region have struggled with health care reform, with each pursuing private care and insurance options to little avail. (Von Schoen-Angerer 2004). With arguments simultaneously forwarded that either HIV estimates vastly underestimate actual prevalence, or greatly overestimate the possible number of individuals affected, the southern Caucasus provide an excellent case study for the examination of the social construction of HIV measurement and knowledge.

## **Methods**

I employ a mixed method approach to examine the four central research questions regarding testing, transmission, sentinel testing, risk group size, and variations in estimates.

To better understand the context in which individuals choose, or are mandated, to be tested, I rely on summary results from regional surveys, national legislation regarding testing, and reported national data concerning the number of HIV tests conducted. Transmission information is assessed using official reports breaking cases down by mode of transmission, interviews with public health workers involved in testing, and in Azerbaijan and Georgia, a short term observations in a testing clinics. Secondary statistics, existing literature, and the US Census HIV data base provide the

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<sup>5</sup> These data rely upon those reported in EuroHIV, 2008. *HIV/AIDS Surveillance in Europe: Mid-year report 2007* No.76. pg. 39. Donor data is also difficult to extrapolate, as in the past reagent shortages have precluded comprehensive screening of all donations and blood donors are not likely to be representative of the entire population.

<sup>6</sup> UNAIDS high end estimate for the region is 40,800, or 16 times the number of officially registered cases.

information for the assessment of sentinel testing approaches and results. Secondary statistics, IGO and NGO reports published between 2002 and 2006, and local media coverage serve as the basis for the examination of risk core group size, and inform overall prevalence estimates. A series of 26 interviews with National HIV/AIDS center staff members, IGO officials, NGO researchers, and public health experts in Armenia (9), Azerbaijan (8), and Georgia (9) conducted in the spring/summer of 2007 assist in addressing each of the four question areas, as did informal discussions with researchers at a June 2007 MAP meeting in Moscow.

While the observations and interviews serve to guide the analyses, the focus of the investigation and preliminary protocols are linked to earlier research examining the socio-cultural correlates of HIV/AIDS in the region. (Buckley 2005A and B) Serving as the chief scientific consultant on a UNESCO project in the region in 2004-05 highlighted the importance of contextual factors in evaluating and interpreting prevalence estimations, understanding testing coverage, and considering the potential biases at work in the generation of estimates for me.

Returning to the region 18 months later as an independent researcher with a pre-structured investigation, I anticipated problems in terms of my own positionality. In preliminary contact with respondents and at the time of interview, I stressed the independent nature of this project, to minimize any influence of previous institutional association. Given the fluid structure of research employment in the region, most respondents were personally familiar with temporary consulting positions, and were open and willing to share both critical and laudatory perceptions of procedures, non-governmental organizations, and local issues. While I had come into contact on previous occasions with 19 of the 28 individuals interviewed, all were aware of the academic nature of the research, and were assured of anonymity to facilitate the open exchange of ideas and opinions.

With the exception of IGO and some NGO representatives who preferred English,

interviews were conducted in Russian, with extensive notes taken during the interview. Interview summaries, based on notes and memory, were prepared within 12 hours of the interviews. Respondents were contacted by phone if there were issues to clarify, or to confirmation of the meaning and wording of any direct quotes to be marked in the transcript. Content from the interviews was categorized into the five question themes, pre-coded within each country, cross coded within each respondent category, and then coded with a summary scheme.

## **Findings**

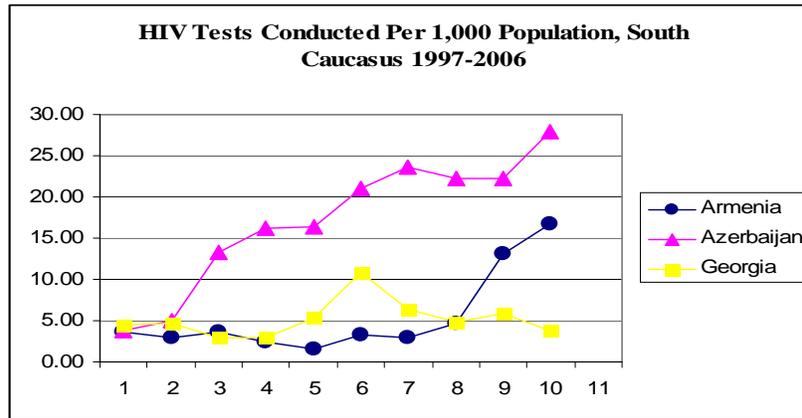
### ***Testing Coverage***

What are the general patterns of testing within the region? How do state regulations (legislation) and public perceptions of HIV influence testing coverage? Figure Three illustrates the wide variation in the region in testing coverage, measured in terms of tests per 1000 population, between 1997 and 2006. Each country in the region has rather modest testing coverage in 1997, but in the last ten years, Azerbaijan, the largest country of the region, reports pursuing more extensive testing than Georgia, which reports the highest absolute and relative number of people living with HIV. Armenia expanded the number of test per 1000 population in recent years, after a decline in 2001 due to a reported shortage of testing materials. But, in the context of a concentrated epidemic, do more tests always translate into better coverage of target populations? Who exactly is “covered” in terms of HIV testing in these three countries?<sup>7</sup>

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<sup>7</sup> Please note, numbers do not include blood screening.

**Figure Three.**



Source: EuroHIV, 1999-2007

Several respondents in Azerbaijan noted that the expansive approach to HIV testing in the country may well represent a misdirection of resources, and mask potential cases by focusing on mandatory testing within populations with relatively lower HIV risk,

Well of course we test a lot, the more the better. Incentives are given to clinics to test patients, whoever. Laws demand certain groups be tested. Why? There is little targeting of the narcotics community, women forced into prostitution aren't being tested, and you mentioned labor migrants, we are only now starting to encourage them to come in and get tested..... Pregnant women, that is who gets tested, or people going into the hospital, or suspicious arrests. The people whose actions make them at risk, we don't see them.

(Epidemiologist, Azerbaijan August 2007)

In contrast, researchers point to an increased interest in obtaining HIV tests among residents of regions believed to have higher prevalence within Armenia. The establishment of regional testing centers<sup>8</sup>, adoption of rapid testing techniques, incorporation of HIV testing with STI (sexually transmitted infection) treatment, and increased knowledge concerning HIV are often mentioned in terms of increasing voluntary testing, especially among non-IDU risk groups.

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<sup>8</sup> Testing points in each of the administrative districts of the countries (Marzes) have been opened.

People come in and want to get tested now, not like before. Our education programs have helped our work in the regions [too]. All Marzi {districts} have testing units and confidential clinics. Of course, people are still sometimes reluctant and there is still stigma, it is embarrassing, but if you are already being tested for STIs, then maybe it is better to know.....Our concern now is keeping supplies on hand, and trying to target the young narcotics community [even] better.

(Medical Doctor and Researcher, Armenia July 2007)

Several respondents attributed Armenia's increased rate of testing to the emergence of demand for voluntary testing, but voluntary testing appears much less common in Georgia. While mandatory pre-natal screening is the norm across the region, as is military screening, Georgia and Armenia have taken softer approaches to required testing in comparison to Azerbaijan. Respondents claim mandatory testing regulations are in effect for arrests linked to CSW (commercial sex workers) or IDU, such as school teachers (in some regions). The relatively low testing prevalence in Georgia is further attributed to a strong distrust of the medical community, a persistently high stigma toward HIV, and a rather fatalistic attitude towards HIV.

You have to understand, HIV is it. That is all. People still do not believe there can get treatment, they view the medical system as a source of infection. These attitudes are like steel.

Social Worker, Georgia (March 2007)

Across the region, surveys find that medical transmission remains the most often identified mode of HIV transmission. Stemming in part from the lasting effect of the first major HIV outbreak in the Soviet Union, which took place in a birthing hospital the provincial town of Elista (Belitsky, 1989), and fueled by vast media attention on cases of transfusion-related transmission, the medical system is best avoided, an attitude perhaps most strongly held in Georgia, where service costs are highest and state medical coverage lowest.

Higher testing coverage may not coincide with better targeting of risk-related populations. In the southern Caucasus, the relatively high testing rates in Azerbaijan appear to be linked with

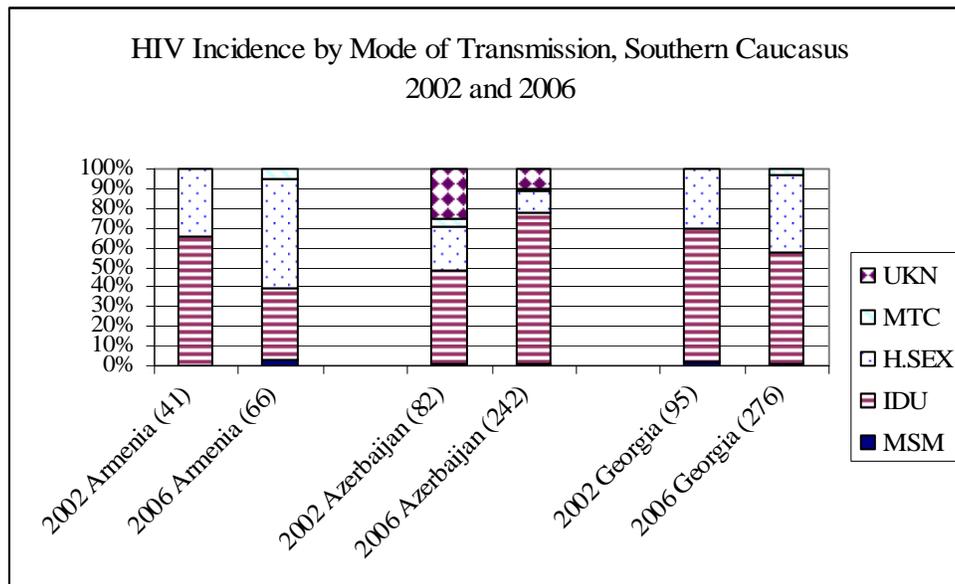
state mandated testing, rather than voluntary testing based on self-perceptions of risk. Survey data in the regions cast suspicions on how individuals may perceive HIV-related risk. Numerous studies have pointed to the persistence of stigma and discrimination and the region, findings confirmed by preliminary findings from regional DHS and RHS studies.

While knowledge of HIV transmission is improving, reported misconception levels remain notable, and are highest among men and women in Azerbaijan. (See Claeys et. al. 2001 for background) Beliefs concerning transmission possibilities, related to social contact or medical exposure, can alter patterns of voluntary testing, and beliefs concerning the efficacy of broad based mandatory testing might similarly influence testing patterns. Further research into who is tested, when, and why is needed to better interpret trends in testing coverage.

### ***Transmission Modes***

How is the route of transmission attributed? How might the processes of attribution influence reported patterns of transmission? Great emphasis is placed on the shifting HIV transmission pattern in the southern Caucasus. (Babayán 2002; Babikian et.al. 2004, UNAIDS 2007) Increasing numbers of new HIV infections attributed to heterosexual transmission might indicate intravenous drug users (IDUs) are serving as a bridge population to sexual transmission of HIV, similar to the experience of Ukraine in their earliest period of rapid growth of HIV infections. (UNAIDS 2007) The growing importance of sexual transmission marks an expansion beyond previous core risk groups in the region, commercial sex workers and intravenous drug users. However, disaggregating results by country shows that in Azerbaijan the percentage on incidence attributed to heterosexual transmission actually declined in proportionate terms, while the actual number of new cases increased.

**Figure Four.**



Source: EuroHIV, 2003 and 2007

As seen in Figure Four, IDU transmission, is proportionately declining in Armenia and Georgia, but rising in Azerbaijan. Transmission attributed to MSM remains rarely reported. Only Azerbaijan reports a significant number of cases without reported mode of transmission. Mother to child transmission (MTC), the target of the majority of mass testing done in the region and easiest mode to identify, is particularly small. Its highest numerical value, six cases, occurs in Georgia in 2006. The overall number of cases identified is expanding rapidly in the region, more than doubling between 2002 and 2006 (from 218 to 584 new cases reported), but the relatively small number of cases means that even slight shifts in the attribution of transmission mode can exert a substantial impact on the national profile. Are the variations in mode of transmission in Figure Four due to alterations in the spread of HIV in the region alone, or might the context in which transmission modes are identified, and the procedures followed for attribution also potentially at play?

The strong stigma associated with MSMs across the region, and particularly in Azerbaijan

may influence both self reports and attribution of this transmission mode. The cultural context of the southern Caucasus is conservative, centered on family and kinship ties. A very high priority is placed upon having at least one child, and on marriage, prompting, in the words of one gay activist in Armenia, “homosexuals to hide in plain sight”, often marrying a woman to “keep up appearances”. Homosexual activities (only vaguely defined) were illegal across the southern Caucasus until the mid 1990s, a remnant of the Soviet legal code. While the Internet has afforded an excellent opportunity for new forms of networking, and there are some indications of greater social acceptance, the MSM communities in the Caucasus tend to be rare, closed, and hidden, unlikely to self-identify when filling out epidemiological questionnaires.

Testing point staff may also influence the recording of likely about transmission mode. During my brief time observing at a testing center, one of the intake counselors in Baku commented that he could identify men who engaged in MSM, and sometimes declined to read that option on the intake form when interviewing. “Azeri men would be furious,” he added, pointing out that only men of other nationalities would participate in “such deeds”. A second staff member in Baku made a similar remark about IDUs, claiming that they were clearly identifiable as drug users upon arrival to the clinic. After some conversation, he confided that often he filled out the intake forms himself “when he was clearly an IDU”, “rather than ask him to admit his shame”. When queried, he shared that women were never IDUs, “even Russian women”. Women gained exposure to HIV from sexual relations with drug using partners, a sentiment reinforced by expert respondents in Armenia and Georgia.

Staff at the testing site in Georgia, admitted that attribution was “imperfect” in Georgia as well, due to both reluctance on the part of clients and “assumptions” in some cases on the part of staff. While no observation in Armenia was possible, a researcher at the Armenian National AIDS

Center stated that they traditionally have proportionately attribute the unknowns across major modes of transmission, reinforcing reported patterns and ignoring the potentially non random distribution of the unknowns.

Tracing incidence patterns by mode of transmission can be problematic in many ways, and caution is called for in the interpretation of shifting forms of transmission, especially at low incidence levels, such as those found in the southern Caucasus. Local attitudes towards and assumptions relating to the appearance, gender, or ethnic ties to specific modes of transmissions can influence self-reporting, and intake record keeping. Social beliefs and traditions influence the process of identification and attribution, thereby influencing the ways we identify and construct individuals “at risk” of HIV infection. Similar processes may factor into the identification of groups for sentinel testing.

### ***Sentinel Testing and Surveillance***

International and local experts agree that HIV in the southern Caucasus tends to remain concentrated among specific sub-populations, primarily IDUs and CSWs and secondarily among individuals with STIs and residents in prisons (who have elevated rates of tuberculosis and assumed higher rates of IDU). Across the region, researchers have actively pursued small and large scale sentinel testing of specific sub populations in order to better assess levels of infection within specific local risk groups, as well as the importance of risk groups identified in other contexts, such as MSMs. The results of these sentinel investigations are then used to target prevention and treatment programs, generating broad based estimation of population prevalence.

Given the difficulties associated with finding and entering many of the subpopulations viewed at high risk, sentinel testing does not rely upon random sampling techniques, often

employing less representative snowball, quota or availability sampling. As seen in Table One, dozens of sentinel testing investigations of various sizes and focus have been completed in the southern Caucasus between 1996 and 2006. The largest number of registered sentinel studies, 138, was completed in the smallest country, Armenia. Reflecting the importance of IDU in driving the expansion of HIV infection in Eurasia, and historically based caution over medical and mother to child transmission, these three sub populations receive the most focus.

**Table One. Sentinel Studies for HIV Prevalence, by County, Sub-Population, Coverage and Sample Size, and Prevalence Estimate, 1996-2006, Southern Caucasus**

Country	Total, 96-06	Sub Population	# of Studies	Sample Min.	Range Max.	Lowest Est.	Highest Est. (Yr/SS)
Armenia	138	Blood Donors	28	16	13,949	0	.04 (2000/2367)
		STIs	26	10	347	0	7.14 (1996/28)
		Pregnant Women	22	303	2,652	0	.06 (1998/1545)
		IDU	17	16	352	0	18.52 (2001/27)
		Prisoners	11	14	851	0	8.79 (2000/182)
		CSWs	9	37	250	0	7.5 (1999/250)*
		MSMs	2	15	108	0	.9 (2000/108)
Azerbaijan	60	Blood Donors	19	674	77290	0	.15 (1997/674)
		STIs	13	109	3113	0	.27 (1996/376)
		Pregnant Women	6	192	64857	0	.7 (1998/9827)
		IDU	12	104	1126	0	19.9 (2003/200)
		Prisoners	2	ukn	3898	0.22	.36 (1998/3998)
		CSWs MSMs	N/A N/A				
Georgia	47	Blood Donors	12	19305	13146	0	.04 (2001/20573)
		STIs	4	ukn	4253	0	.45 (2002/1104)
		Pregnant Women	4	810	6699	0	0 22.2
		IDU	9	203	1895	0.04	(2001/207) 1.82
		Prisoners	3	220	6733	0.07	(2005/220) 1.4
		CSWs	3	ukn	158	1.27	(2004/ukn) .05
		MSMs	1	ukn	182	0	(2005/182)

\* study of registered prostitutes

Sources: <http://hivaidssurveillancedb.org/>

As seen in Table One, sentinel studies of specific sub-populations in the southern Caucasus vary dramatically in sample size and the prevalence estimates generated. Many of the highest estimated prevalence findings were generated in studies with very modest sample sizes. The most frequent target group for sentinel study is blood donors, perhaps linked to reported difficulties in attaining complete blood screening in the region. (Butashvili et.al. 2001; Kressler 2001)

Similarly, the monitoring of pregnant women has been expansive in each of the three countries of the region. Multiple studies have focused on the IDU community, but the sample sizes, national scope, and resulting estimations have varied dramatically from study to study. Directed investigations of MSM communities, or of CSWs tend to be far more limited, and additional studies of prison populations in both Georgia and Azerbaijan appear clearly warranted.

A major challenge to reliable and valid sentinel surveillance is sample construction. In the three small countries of the southern Caucasus, social networks are often overlapping. Members of risk related groups in specific locations, and even across space, may know each other, share friends and acquaintances, and engage in risk-related behaviors with one another. In such circumstances, adding social networking measures into sentinel surveillance approaches becomes especially important. Testing small targeted samples, may simple result in the measurement of one node or transmission network.

{Our study of prostitutes last year.} It took a long time to find the girls, and convince them to help us to get tested. We spotted girls on different nights, in three different sections of the city. Talking with them it was clear many either know of one another, or were no more that one or two people apart from knowing each other. Four of the girls seemed to have overlapping clients, at least they thought so. Yes, they compete with one another, and are rough, but they are still linked into each other.  
Epidemiologist, Armenia (July 2007)

You must remember that drug use here in Georgia is different, it is not like other places. Things change, but most people use drugs in small, highly trusted networks, not random groups in abandoned buildings. The good thing is, there should be less risk, the bad news is if one brings infection to the group, it spreads very quickly. Changing behavior is like breaking trust, it is costly.

Psychologist, Georgia (March 2007)

Using sentinel surveillance techniques on a small number of networks or behavioral nodes will tend to generate prevalence estimates that are either quite high, or quite low, depending on the exposure possibilities in the network. This risk appears clear in studies of prison populations, with the individuals being studied share living conditions, and supposedly some level of risk exposure. Building in an additional social networking focus to sentinel surveillance in the region would be beneficial for the evaluation of prevalence estimates, while also informing our understanding of risk behavior patterns and linkages across population sub-groups. Sentinel study findings to date vary significantly, precluding precise understandings of concentration levels within specific populations and clear descriptions of changing patterns over time.

### **Estimating the Number of People Engaged in Risk Related Behaviors**

What are the approaches used to estimate the size of groups engaging in risk-related practices? How do they reflect local customs, perceptions of stigma, and gender norms? While improved sentinel surveillance may generate better understanding of prevalence rates within specific sub-populations, their extrapolations into prevalence estimates for national populations depend upon reasonable assumptions regarding the size of the sub-population. Several of the population groups examined in the previous section are, for the most part, readily identified and quantified; prisoners, pregnant women, blood donors, and individuals with diagnosed STIs. Other sub-populations, such as commercial sex workers, IDUs, and MSM are far more difficult to

reasonably estimate. Dire poverty in the region has been linked with increases in short term commercial sex work, in particularly in Armenia (Nijaradze et.al. 2005), complicating the estimation of the number of women involved in sex work. Diverse levels of engagement in sex work reflect important variations in the context of work, control over negotiations (condom and otherwise), and number of clients, all factors directly influencing risk.

One approach to clarify both the identity of the sub-population and the number of individuals within it has been employed in Armenia in term of sex workers. They differentiate registered sex workers, women who have been arrested for engaging in sex work, or self-identified when receiving STI testing and treatment, from the more general category of CSWs. While this delineation fails to include many CSWs who are at elevated risk, it has the benefit of clearly identifying the size of the sub-population and is believe to identify CSWs with the largest client lists and longest terms of exposure.

A different approach is followed in Azerbaijan, where CSWs serving foreigners are often targeted. In keeping with the perspective that HIV is an illness from the outside, CSWs serving foreign clients are viewed as the highest risk category among sex workers. Even though the number of clients served may be relatively low, and the age of CSWs engaged in this occupation tends to be young, outsiders are viewed as much higher risk than locals. Across the region, all approaches to the estimation of individuals engaged in commercial sex work include only women. Among my respondents, several individuals in Azerbaijan mentioned issues of ethnicity and CSW, pointing out that non-Azeri ethnicities were over-represented within the CSW populations, but specific data to support such claims is thin.

The size of the IDU population within the southern Caucasus is also extremely difficult to estimate. Narcological registries, first established during the Soviet period, exist in each country of

the region, but grossly underestimate the true number of IDUs. While registration enables individuals better access to treatment, and in some cases a very modest social pension, it also entails the permanent loss of one's drivers license and is retained as a part of an individual's permanent social registration. (DLHPR 2002)

Targeting sub populations to determine IDU prevalence is difficult in the southern Caucasus. The correlation between IDU and lower social status found in many places in Europe and North America does not operate in the same way in the Caucasus, where IDU is spread throughout the middle and upper classes, and bears no significant link to education level. (UNAIDS 2007) While, unlike drug use, men having sex with men is no longer legislatively criminal in the Caucasus, it remains heavily stigmatized and hidden.

Many changes have taken place, but some things are exactly as they were. Just as in Soviet times, we have no prostitution and no drug problem. MSMs, you know they are simply a sign of western decadence. Sex is permissible for conceiving children, ideally 2 boys and 1 girl. Simply so, all problems solved.  
(Researcher, Azerbaijan, March 2007)

## **Conclusion**

In this paper I explored the way in which what we know epidemiologically is constructed within the constraints of the meanings of disease and the social beliefs (regardless of their accuracy) associated with illness related behaviors and social norms. The wide variation in estimated prevalence of HIV in the southern Caucasus, lack of clarity in the measurement of transmission mode, wide variation in sentinel surveillance results, and the lack of consensus on the number of individuals engaged in risk related behaviors are likely to preclude the precise estimation of the severity of the regions HIV infections, hindering the adoption of evidence-based policy approaches. Examining the ways in which the social meanings and mythologies influence the

estimation of HIV prevalence in a region with relatively low, but sadly growing, HIV incidence can improve our understanding of the strengths and weaknesses of present estimation techniques, and hopefully add to current discussions and debates concerning HIV estimations in high prevalence societies, and across the globe.

Current debates concerning institutional incentives for higher or lower prevalence estimates of HIV are important, and may assist in the clarification of widely varying estimates of prevalence and projections concerning HIV/AIDS. In addition to examinations of institutional incentives, greater attention as to how the local cultural influences the testing patterns, methods of transmission attribution, sentinel testing techniques, and the identification and estimation of risk groups is similarly justified. In countries with rapidly growing, yet numerically small, HIV incidence even modest variations in monitoring, transmission attribution, and overlapping networks within sentinel studies are capable of exerting substantial influence on resulting estimates and projections for the future.

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