Assessing the Public Health Response During and After the Emergency: Lessons from the HIV Epidemic

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ASSESSING THE PUBLIC HEALTH RESPONSE DURING AND AFTER THE EMERGENCY: LESSONS FROM THE HIV EPIDEMIC

ZITA LAZZARINI*

INTRODUCTION

“Be prepared”1 – familiar to many from the scouting handbooks – is one of the most common, if not ubiquitous pieces of advice in the modern world. The American Public Health Association promotes preparedness in its advocacy, professional education, and outreach activities.2 It is unsurprising then, that preparedness – for disasters, epidemics, or even financial crises – has emerged as one measure of good government. Thus, the degree to which our cities, states, and federal governments are prepared for the unexpected is part of regular civil discourse.3 Governments can be

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3. See James Kanter, Europe Takes a Big Step to Avert Economic Crises, N.Y. TIMES, September 4, 2010, at B3 (describing efforts by European governments and Central Banks to create trans-national agencies to prevent another financial crisis); David Leonhardt, Heading
praised or (more often) blamed for the alacrity of the collective response to emergencies.4

We usually think of “preparedness” for pandemics or other emergencies primarily as actions taken before a pandemic strikes. Assessments of preparedness may measure capacity, authority, knowledge, and/or inclusion of best practices in planning a response, among other factors.5 However, it is also critical to assess what happens after the pandemic strikes: to measure how the (hopefully) well-designed plans were executed; to measure whether the capacities developed in the planning phase actually met the needs of public health personnel during the epidemic itself; and, importantly, to consider where implementation of existing laws, policies, or practices may actually undermine an effective response.

This article will use the experience of the Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome (HIV/AIDS) epidemic to illustrate how assessing implementation of public health laws, policies, and practices can demonstrate both successes and failures of preparedness and implementation. Part I will lay out a model that illustrates the role of assessment throughout the emergency, from readiness before an event, through the actual emergency itself and, in an ongoing way, as part of efforts to evaluate and improve the response. Part II will review examples of each possible stage at which assessments can be conducted, from examples of current scholarship that assess public health legal preparedness prior to an event to the range of methodologies that have been used to retrospectively assess preparedness. These assessments include those that

Off the Next Financial Crisis, N.Y. TIMES MAG., March 28, 2010, at 37-38 (describing how elements of President Obama’s plan would reduce the likelihood of future crises).


identify apparent gaps in the law, document legal and public responses that facilitate or interfere with a sound public health response, and include implementation studies. Part III will look specifically at research regarding the readiness of the legal system to confront HIV/AIDS and the response of the legal system since the epidemic. This will include the role of legal research early in the epidemic, focusing on the adequacy of “law on the books,” as well as research that integrates empirical methods (both qualitative and quantitative) to evaluate the implementation of laws that impact HIV prevention and treatment efforts. Part IV describes the use of rapid policy assessment to evaluate implementation of criminal law in relation to HIV prevention efforts in four countries in Eastern Europe, the Former Soviet Union, and Central Asia.6

I. ASSESSING LEGAL PREPAREDNESS AND RESPONSE TO EMERGENCIES

When asked by Dr. Evil “what kind of legal system would be most vulnerable to a bioterrorist attack,” Rumpole the Malevolent answers,

Your ideal legal target for a bioweapon attack is a country that . . . has a fragmented legal system in that relevant legal powers to respond to a public health emergency are divided among actors at the national and local levels . . . . [Y]our ideal legal target should manifest a long, historical neglect of public health law concerning infectious diseases . . . . [Y]our ideal legal target would be a legal system that emphasizes the protection of individual rights and restricts governmental powers to impinge on such rights . . . . [and, finally] a legal and political system that has neglected its public health infrastructure and personnel for decades . . . .7

The U.S. public health system is a highly complex combination of public and private institutions, laboratories, agencies, and procedures that relies on a wide range of scientific disciplines (biostatistics, epidemiology, behavioral and environmental sciences, immunology, virology, and computer modeling) and touches peoples’ everyday lives in the form of the food they eat, the water they drink, standards for sanitation, licensing of health professionals, mandated vaccinations, preventive health screenings, and scores of other ways. In the U.S., public health law structures the public health system in numerous ways. Public health law is shaped, and some

6. The rapid policy assessment discussed in this part of the paper was supported by NIDA/NIH Grant #5 R01 DA17002-01 (2003-2010). Principal Investigator: Zita Lazzarini; Co-Investigators: Patricia Case (Fenway Health Institute) and Scott Burris (Temple University Law School); Project Manager: Repsina Chintalova-Dallas (Fenway Health Institute). However, the findings and conclusions expressed are those of the authors and not necessarily of NIH, NIDA, or the U.S. Government.

would say constrained, by the nature of democracy and our constitutional system of checks and balances, which might sometimes deter a rapid public health response as much as it deters would-be tyrants. Public health law structures the responsibilities and powers of public health authorities by setting the public health agenda; granting authority to public health officials; setting limits on that power; and acting as a tool of public health enforcement.

A public health legal framework, trained personnel, and adequate resources are critical for society to respond to emergencies, disasters, and pandemics. These events, whether natural or man-made, strain the capacity of the system to respond, either due to the numbers of sick or injured, destruction of infrastructure, or contamination of vital resources.

As part of their responsibilities, public health officials must assess their own preparedness, including the capacity to prevent, respond, and adapt to public health emergencies of all kinds. When and how should assessment happen? These are critical questions for those tasked with designing systems in advance and evaluating them after an event. In this article, I argue that preparedness and assessment should both be seen as continuous rather than static or time-limited processes. As such, preparedness should be conceptualized as not only the accurate anticipation of and planning for emergencies, but also the ability to

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8. See id. at 81.
12. See, e.g., Nelson et al., supra note 5, at 10-11 (suggesting that public health preparedness, as a discipline or area of measurement, is in its infancy and that emerging methods of assessment of preparedness include “embedded assessments” – in which preparedness assessments are built into ongoing or periodic activities – and “look back” assessments – in which an agency’s response to an event is evaluated retrospectively in order to find ways to improve preparedness for future events).
respond, adapt, and modify systems over time so that their actual function meets the needs of the unfolding events. Figure 1 illustrates one model that links a timeline of an emergency to domains of inquiry that contribute to effective ongoing assessment of preparedness and response.

Figure 1. Assessing Preparedness and Response to “Emergencies”

II. STAGES OF ASSESSMENT

Type 1 assessments, illustrated above, pose questions of preparedness before an event – are we, as a society, city, community, or nation prepared for a public health emergency? Many scholars in public health have contributed work in this area, including frameworks for assessing legal competencies, evaluating public health laws and legal authorities, examining information and best practices, and considering critical questions of coordination across jurisdictions and disciplines as part of legal preparedness. Others have contributed significant scholarship and

14. See, e.g., Hodge et al., supra note 5, at 28-34.
Empirical research over the last decade. The goals of Type 1 research are broadly to identify and measure progress towards achievement of “legal benchmarks within a public health system.” Examples of these types of benchmarks include: the development and adequacy of sources of legal authority to enable public health officials at the state and local level to respond to emergencies; the definition of substantive competencies in the fields of public health law and ethics as a discipline, which could provide the basis for measuring levels of knowledge and skills of these professionals; and the availability of information resources about public health legal preparedness, including where the absence of information might prevent public health officials (and their legal colleagues) from being able to respond to an emergency. These benchmarks provide some of the measures to evaluate the readiness or capacity of the public health system to respond to emergencies. From a legal perspective, such a system should include: structures/systems sufficient to meet anticipated needs for a variety of emergencies; the presence of a trained workforce; emergency response plans that anticipate legal issues; and mechanisms and judicial or other expertise that may be necessary to resolve those issues in a timely way.

Type 2 assessments focus on the immediate response during the acute phase of an emergency. The goals of this type of assessment include: measuring time elapsed in initial response (when that is important); usefulness of early warning systems (if applicable); problems in identifying or confirming a threat; and adequacy of the initial response. At this point in

20. See Kamoie et al., supra note 15, at 23.
21. See id. at 24 (describing the laws related to disaster preparedness and responsiveness at the state and federal level).
22. Hodge et al., supra note 5, at 29.
24. See Leeb, Chrysler & Goodman, supra note 19, at 77-78.
the response to an emergency, research does look at implementation, but its findings are necessarily limited to the first stages of the response. It is often difficult to measure actual effectiveness of the response, identify missed opportunities to mitigate the problem, or accurately describe the long-term impact of measures taken at the outset either because the time period of assessment is relatively short, or the goals of the assessment are limited.

Type 3 assessments are particularly concerned with identifying unanticipated barriers caused by the legal system or, conversely, factors that make the law particularly effective. This type of implementation research looks at the law and practice over a longer period of time, uses mixed methods (legal research, quantitative and qualitative measures), and incorporates information on how individuals experience the law’s application or enforcement. These research studies do not, however, usually include introducing new ways to reduce barriers that are detected or capitalize on practices that were successful. To borrow a metaphor from medicine or public health, Type 3 assessments are “diagnostic,” but not “curative.”

Type 4 assessments focus on making improvements or modifications based on the data derived from studies of Types 1-3. In these types of assessments, researchers not only actively identify barriers and facilitators of effective implementation, they also propose and, ideally, test modifications, innovations, or responses that aim to bring the actual practices into alignment with public health goals. This type of assessment is obviously critical to the long-term monitoring and improvement of the public health legal system. These studies provide evidence for improvement of public health law in a number of ways—from merely enhancing implementation of the original laws, to suggesting “work-arounds” for legal conflicts, and perhaps to support efforts for legislative change.

MORBIDITY & MORTALITY WKLY. REP. 939, 943 (2010) (describing the lessons learned from the creation of a National Sentinel Surveillance System in Haiti after the 2010 earthquake).

27. See, e.g., Fisher, supra note 19, at 209-10 (identifying and evaluating the legal barriers to effective response to disasters that may require a response from institutions and individuals across international borders. The International Federation of Red Cross and Red Crescent Societies (IFRC) conducted a global assessment of legal authorities and spent seven years studying legal issues that arose in actual disaster response efforts. This process represents both Type 3 and 4 assessments since the individual assessments described in the study would be more like Type 3, while the overall study included development of new international guidelines and was more similar to a Type 4 assessment).


30. See id. at 211.

The wide scope of public health law research encompassed by this model of “assessment” illustrates the potential interconnectedness of inquiries that might otherwise seem completely separate or unrelated. Efforts to reduce HIV infection among commercial sex workers, for example, might focus in part on housing laws, access to credit for women, or laws regulating the activities of non-governmental organizations.

Public health law research can contribute important data to evidence-based policymaking—these data come in many types and sources. A review of the public health preparedness literature (not law-specific) found that most articles were not empirical and thus failed to contribute to a strong evidence base for future decisions. This problem is even more acute in public health law research related to preparedness.

III. ASSESSING LEGAL PREPAREDNESS AND RESPONSE TO HIV/AIDS

The virus of which I speak [HIL] is not a physical one, detectable under the microscope in a laboratory. It is nonetheless a tangible development that may be detected in a growing number of societies. In some ways it is as frightening and dangerous as the AIDS virus itself. It attacks not the body of an individual victim, but the body politic.

* HIL = highly inefficient laws

A. The Role of Legal Research

The identification of AIDS and the scientific community’s subsequent realization that AIDS was a global epidemic unleashed a worldwide rush of lawmaking, referred to by Justice Michael Kirby as an “epidemic.” The first national AIDS law was adopted by Swedish lawmakers in 1983, only two years after the first cases were identified and two years before HIV tests (describing how California legislation legalizing syringe exchange in counties may contribute to improvements in public health by allowing these populations to practice without fear of reprimand).

36. Id. at 304.
became widely commercially available.\textsuperscript{37} Research on AIDS-related laws commenced immediately.\textsuperscript{38} This section describes how the notion of assessment of preparedness and response runs throughout that research.

In the context of an unfolding epidemic similar to HIV, legal research can have multiple aims: (1) identifying issues – exploring and defining sources and the extent of public health authority in control of AIDS, including gaps in the legal infrastructure; (2) legal epidemiology – identifying and describing the concrete legal response (in courts and legislatures) to the evolving epidemic; (3) implementation research – examining the actual impact of laws and court decisions using public health empirical methods (plus modeling theories of why people act in certain ways in response to laws); and (4) response research – bridging the gap between implementation and intervention models by identifying and testing modifications of legal response to optimize public health outcomes. In the course of the HIV epidemic, legal research has played a critical role through each of these paths. Throughout this section, reoccurring issues in HIV prevention will be considered from the perspective of differing types of assessments. These include: the use of criminal law to punish HIV exposure and transmission; regulation of syringes; and the role of policing in HIV prevention among drug users.

The public health system, and indeed public health law, was unprepared for an epidemic of a new infectious disease when the cases, later recognized as AIDS, were first identified.\textsuperscript{39} The emergence of a deadly new disease, first identified among gay men and drug users,\textsuperscript{40} raised troubling questions

\textsuperscript{37} Katarina Tomasevski et al., AIDS and Human Rights, in AIDS IN THE WORLD 537, 547 (Jonathan Mann et al. eds., 1992).

\textsuperscript{38} See id.

\textsuperscript{39} Ruth L. Berkelman et al., Infectious Disease Surveillance: A Crumbling Foundation, 264 SCIENCE 368, 368 (1994) (describing grave shortages of specific disciplines and skills among state public health personnel). See, e.g., LAURIE GARRETT, THE COMING PLAGUE: NEWLY EMERGING DISEASES IN A WORLD OUT OF BALANCE 412-13 (1994) (describing the emergence of infectious diseases in the last quarter of the twentieth century in spite of earlier successes in public health including development of vaccines and antibiotics). See also LAURIE GARRETT, BETRAYAL OF TRUST: THE COLLAPSE OF GLOBAL PUBLIC HEALTH 122-24, 286-87 (2001) (describing a lack of resources and focus of public health systems in both western and former Soviet states); Anthony S. Fauci, Emerging Infectious Diseases: A Clear and Present Danger to Humanity, 292 JAMA 1887, 1887 (2004) (describing the current threats posed by infectious disease, both natural and products of bioterrorism. The author notes that the development of antibiotics and vaccines had led to a false sense of complacency, such as that reportedly expressed by the U.S. Surgeon General in 1967 that “the war against infectious diseases had been won,” a statement that turned out to be woefully premature.).

\textsuperscript{40} Ctrs. for Disease Control & Prevention, Current Trends Update on Acquired Immune Deficiency Syndrome (AIDS) --United States, 31 MORBIDITY & MORTALITY WKLY. REP. 507 (1982), available at http://www.cdc.gov/mmwr/preview/mmwrhtml/00001163.htm; Ctrs. for
about how public health officials should respond, as well as how the response ought to be codified in law at the federal, state, and local levels both in the U.S. and abroad. 41 Although a complete recounting of all the legal issues debated early in those years is beyond the scope of this article, mentioning a few may illustrate both how much has changed and how much has stayed the same since the early days of the epidemic.

1. Descriptive and Analytical Studies

By the end of the 1980s, nearly 200 statutes related to AIDS and HIV were enacted in the U.S. 42 States grappled with questions related to core public health functions of testing and screening, surveillance, and public health authority to regulate businesses. 43 Key issues included: whether screening and testing for HIV should be voluntary, routine, or compulsory; 44 whether HIV should be classified as a sexually transmitted disease for the purposes of state public health control efforts; 45 and whether courts could and should grant health officials’ requests to close gay bathhouses. 46 In


43. Id.

44. See, e.g., Ronald Bayer, *Clinical Progress and the Future of HIV Exceptionalism*, 159 ARCHIVES INTERNAL MED. 1042, 1043-46 (1999) (discussing the impact that clinical advances in HIV care and prevention have had on the ethical justifications for certain policies, focusing on screening of pregnant women and reporting cases of HIV by name to state health officials); Renée Danziger, *An Epidemic Like Any Other? Rights and Responsibilities in HIV Prevention*, 312 BRITISH MED. J. 1083, 1083 (1996) (discussing the need for responsible HIV prevention and mandatory HIV testing); Carol Levine & Ronald Bayer, *The Ethics of Screening for Early Intervention in HIV Disease*, 79 Am. J. Pub. Health 1661, 1663-65 (1989) (describing ethical concerns raised by different testing regimens and recommending voluntary testing based on full informed consent for almost all situations).

45. N.Y. State Soc’y of Surgeons v. Axelrod, 572 N.E.2d 605, 606-10 (N.Y. 1991) (Four medical associations in New York sought to force the New York Commissioner of Health to classify HIV/AIDS as a communicable and sexually transmissible disease, as defined by the New York Public Health Code. New York’s highest court held that the decision as how to classify HIV/AIDS was within the discretion of the Commissioner.).

addition, courts considered contentious issues such as whether children’s right to know or parents’ rights to control the education of their children should prevail when weighing the incorporation of HIV prevention education into public school curricula, and whether criminal law should be used to punish intentional or negligent exposure to HIV through sexual or other contact.

A common thread among many areas of debate was the tension between using the law as a tool to mitigate the stigma of HIV/AIDS and a more traditional focus of the public health law – combating the epidemic by identifying the sick and protecting the healthy. Specifically, whether and to what degree anti-discrimination law should be used to protect persons with HIV, including whether physicians and other health care professionals have a duty to treat persons with HIV, and whether public health officials should take steps to protect drug users from HIV through needle and syringe distribution programs.

Internationally, lawmaking in response to HIV/AIDS flourished as well. In fact, by 1990, at least 104 countries had adopted HIV-specific legislation. Common areas of legislative activity included: HIV testing and surveillance measures; requiring reporting of AIDS cases (and later HIV cases) to state authorities; blood safety; and granting public health authorities coercive powers. Other measures included targeted testing of perceived “high risk groups” accessible to public health authorities such as prisoners, sex workers, drug users, or even pregnant women and military recruits. Provisions to protect confidentiality and prevent discrimination were adopted in many jurisdictions in response to reported abuses. However, anti-discrimination legislation alone remained ineffective unless accompanied by possible legal remedies, enforcement mechanisms, and a population aware of their rights and ability to access legal services.

47. Gostin, Public Health Strategies, supra note 41, at 1624.
48. Id. at 1627.
51. Tomasevski et al., supra note 37, at 543.
52. Id. at 547, 551-60.
53. Id. at 547, 558-59.
54. Id. at 547.
55. Id. at 548-49.
56. Tomasevski et al., supra note 37, at 552-58.
57. Id. at 561-67.
While the sheer scope of the response suggested that governments were “doing something about AIDS,” a substantive analysis of the legislative activity pointed to some disturbing trends. As Justice Michael Kirby noted above, the proliferation of laws may actually interfere with the response to the epidemic.\(^5\) Specifically, he argued that three types of legislation, popular at the time, actually hindered an effective public health response including programs (proposed or adopted) for mandatory HIV testing of: (1) entire populations; (2) certain vulnerable (and usually marginalized) groups; and (3) immigrants, migrants or travelers.\(^6\) Without the possibility of treatment or availability of a vaccine, universal testing, in particular, “would simply provide an extremely expensive, universal epidemiological data base.”\(^7\) Moreover, widespread testing in the absence of strong confidentiality and anti-discrimination protections could offer a tempting source of information for more sinister purposes.\(^8\) In countries (many at the time) where homosexual acts constituted a crime, merely testing positive could be interpreted as having committed a crime.\(^9\) Drug enforcement personnel might also be interested in HIV testing information as it could implicate persons who used illegal drugs.\(^10\) Discrimination, frequently a response to epidemics, and the further stigmatization of disfavored groups could increase.\(^11\)

Targeted testing, while potentially more efficient than universal testing, only heightened the vulnerability of those tested, since they were often foreigners, or otherwise “despised” minorities.\(^12\) In short, the benefits of testing (epidemiological information and an opportunity for education and prevention) would be significantly outweighed by the risks.\(^13\)

Provisions requiring HIV-free certificates to cross borders raise other issues. The International Health Regulations have long provided guidance to countries on the control of communicable disease and other health risks,

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58. Kirby, supra note 35, at 311.
59. Id. at 308.
60. Id.
61. See Tomasevski et al., supra note 37, at 559 (noting that the disclosure of the identity of HIV-infected individuals has led to loss of employment, housing, and insurance, as well as increased ostracism and suicide rates).
63. Of course police normally do not need such a list to identify drug users since local users are usually well-known to the police. However, police and prosecutors might use lists of HIV-infected persons to prosecute ordinary drug users for additional offenses, including knowing exposure of others.
64. Kirby, supra note 35, at 309; Tomasevski et al., supra note 37, at 551-52.
65. Kirby, supra note 35.
66. Id. at 309-10.
including requiring health exams or records of specific immunizations before entering a country.\textsuperscript{67} However, the choice, by some countries,\textsuperscript{68} to require either HIV testing or HIV-free certificates, is problematic for several reasons. First, not all persons with HIV pose a risk of transmission; since HIV (unlike tuberculosis or yellow fever) is not transmitted by either casual contact or mosquitoes.\textsuperscript{69} Second, testing or certificate provisions sometimes applied only to persons from countries known to have a higher prevalence of HIV, or applied only to some categories of travelers (most often international students or guest workers, but not tourists).\textsuperscript{70} As a public health intervention, these types of testing policies are ineffective. Although HIV prevalence varies significantly from country to country,\textsuperscript{71} virtually all countries have some reported cases.\textsuperscript{72} Therefore, a program that tests travelers and immigrants from some countries but not others will necessarily let some infected persons through. Exempting tourists also provides imperfect protection. In fact, some studies suggest that tourists may be more likely to have unprotected sex or use drugs while traveling than other types of travelers.\textsuperscript{73} So, if the goal were to prevent persons with HIV from entering a country and exposing others, a selective testing policy, which exempts the carefree vacationer would fail to achieve its goal.

At the end of the 1980s, the AIDS Litigation Project produced a two-part report that collected and analyzed all reported HIV-related court cases in the

\textsuperscript{67} World Health Org., International Health Regulations (2d ed. 2005), available at http://whqlibdoc.who.int/publications/2008/9789241580410_eng.pdf. (The International Health Regulations (IHR) were first introduced in 1969 and specify what diseases a country may include in its requirements for crossing international borders.).

\textsuperscript{68} Until January 2010, countries with a ban on travel by some or all types of visitors with HIV infection included: Armenia, Brunei, China, Iraq, Libya, Moldova, Oman, Qatar, Russia, Saudi Arabia, South Korea, Sudan, and the United States. The U.S. repealed its ban effective January 4, 2010. See Report of the Int’l Task Team on HIV-Related Travel Restrictions, Joint United Nations Programme on HIV/AIDS, Mapping of Restrictions on the Entry, Stay and Residence of People Living with HIV 8 (2008).


\textsuperscript{70} See Kirby, supra note 35, at 310.

\textsuperscript{71} UNAIDS, AIDS Epidemic Update December 2009, 19, 57 (2009) (demonstrating HIV seroprevalence variance among nations and populations. For example, some countries in Africa have double-digit prevalence in the general population, including South Africa 16.9\% (2008), Swaziland 25.9\% (2006-2007), and Botswana 25\% (2008), while others have relatively low and stable levels of HIV. In 2009, Latin America as a region was estimated to have 0.6\% HIV infection in the general population.).


\textsuperscript{73} See R. Vivancos, I. Abubakar & P.R. Hunter, Foreign Travel, Casual Sex, and Sexually Transmitted Infections: Systematic Review and Meta-Analysis, 14 INT’L J. INFECTIOUS DISEASES e842, e850 (2010). See also Kirby, supra note 35, at 310.
U.S. from 1981-1989. The author identified 469 cases filed, pending, or decided that involved AIDS or HIV-related issues—a total that he asserted represents “the largest body of legal cases attributable to a single disease in the history of American jurisprudence.” Gostin noted that the cases reported affected key institutions including health care, schools, insurance, public health, and law enforcement. The impact of some of the cases promised to be far-reaching, while in others the public health benefit was likely marginal, including high profile cases of prosecutions of individuals for exposure to HIV.

2. Legal Epidemiology

“Legal epidemiology” documented the legal response to the epidemic in both legislatures and courts. These studies provided basic descriptive information about the characteristics and prevalence of laws before these were easily accessible electronically, and analyzed the legislative content from a normative perspective (what was “good” and “bad” about the laws). Additionally, in our common law system, studies that track litigation in a new field, such as HIV/AIDS, can both identify legal trends in the interpretation of constitutions, statutes, and regulations, and also serve as an indirect measure of public attention to an issue. For example, by indicating where the public, through its prosecutors, chooses to focus its efforts. Where prosecutions are highly selective, such as for exposure to HIV infection, they depend on prosecutorial discretion. Such discretion may be based on many factors, such as perceived need, allocation of scarce resources, or chance. Prosecutions can also respond to local fears or political agendas. Although it may be impossible to identify the reasons for exercise of

76. Id.
78. Gostin, Litigation Project, Part I, supra note 74.
prosecutorial discretion, where prosecution is rare and not based on clear criteria, the fairness and effectiveness of the law may be questioned.

Surveys of laws in a specific substantive area can serve as a starting point for public health legal research. For example, it would have been difficult to have a well-informed discussion of the possible impact of laws and regulations governing syringe sale and possession in the U.S. without first conducting basic research to identify and describe the law in all relevant jurisdictions. Thus, in the 1990s, public health scholars provided descriptive and analytical articles on the law underlying syringe regulation, privacy, water quality, public health powers, and other areas of HIV-related law. These articles started with basic “legal epidemiology” – identifying the relevant laws in all jurisdictions and describing their characteristics. Although this sounds simple, such studies provided a basis for accurate discussion, analysis, and advocacy. These studies provided basic data for legal research – they described the “law on the books,” or the specifics of the law (and regulations) as they were written.

Practically, however, “law on the books” studies do not reflect how the law is actually applied or implemented. Similarly, they do not address how legal actors, including the police and judges, interpret the law or the nature and characteristics of the public’s or defendants’ beliefs about the law.

B. Empirical Methods and Legal Research

In medicine and public health, researchers and policymakers have increasingly sought “evidence-based” interventions as a way of identifying effective strategies to cure and prevent disease, as well as to modify human

81. Lazzarini, Bray & Burris, supra note 79, at 247.
82. Id. at 247, 250.
85. See, e.g., Lawrence O. Gostin et al., Water Quality Laws and Waterborne Diseases: Cryptosporidium and Other Emerging Pathogens, 90 AM. J. PUB. HEALTH 847, 848 (2000).
86. See, e.g., Gostin, Burris & Lazzarini, supra note 9, at 110.
88. Note, the articles described in notes 83-87, above, often also identified gaps or conflicts in the laws as well as potential ways laws might act as barriers to public health efforts.
behavior in ways that makes society healthier. In fact, public health researchers (non-lawyers) have long integrated a wide range of public health methods into research linking laws and behavior. For example, Koester showed that injection drug users (IDUs) in Colorado reused syringes, not because it was part of a drug use-related ritual or bonding experience, but because they perceived carrying their own syringes as dangerous and as providing evidence the police could use to arrest them. Case, Beckett & Jones demonstrated that following the repeal of the prescription requirement for syringe sales in Maine, many pharmacists were still reluctant to sell syringes to suspected drug users because they feared violating the state’s drug paraphernalia law, or did not perceive themselves as playing a role in HIV prevention efforts. Researchers at Yale demonstrated that syringe exchanges played a useful role in decreasing HIV transmission among drug users. Heimer and colleagues showed that changes in syringe law in Connecticut (Connecticut laws were changed to permit syringe exchanges in 1991 and over-the-counter sale in 1993) resulted in changes in syringe sharing, particularly among HIV infected IDUs. Considered together, these studies involved a wide range of data types and sources from qualitative interviews to laboratory methods used to test syringes for drug and virus residue.

89. See Burris et al., Framework, supra note 32, at 170 (describing the need for public health law research to create an evidence base); David Kindig & John Mullahy, Comparative Effectiveness—of What?: Evaluating Strategies to Improve Population Health, 304 JAMA 901, 901 (2010) (arguing for comparative effectiveness research that takes into account the population perspective).


93. Id. at 69.


95. Heimer, supra note 92, at 69.
Sociologists of law have also used empirical methods to examine how law works and why people obey (or fail to obey) the law. 96 For example, their work has been particularly important in developing theories about factors that influence individuals’ response to criminal laws. 97 This has led to important links between fields of social science concerned with human behavior and legal academics.

While researchers have begun to build an empirical evidence base for or against various public health laws, a disconnect may exist between the evidence developed and the actual laws adopted by legislators. For example, many U.S. states’ legislatures have adopted HIV-specific criminal laws to punish HIV exposure or transmission without any concrete evidence that the provisions work to decrease transmission of HIV. 98 Such laws have become popular internationally after a “model HIV law” was created by lawmakers in West Africa working with the U.S. funded group, Action for West Africa Region HIV/AIDS Project (AWARE-HIV/AIDS), that included HIV-specific criminal provisions for persons who knowingly expose others to HIV. 99 Subsequently, at least nine countries have adopted the model law’s criminalization approach. 100 Recent research, however, casts doubt on the efficacy of HIV-specific provisions, in the United States. No evidence of effectiveness was found in a study of the impact of subjects’ beliefs about the law and the actual laws in their state, and their subsequent HIV risk behaviors. 101


97. See Zimring & Hawkins, supra note 96, at 7; Tyler, Public Trust, supra note 96, at 215-16.

98. Lazzarini, Bray & Burris, supra note 79, at 239, 241.


100. Burris & Cameron, supra note 99.

IV. RAPID POLICY ASSESSMENT AND RESPONSE

‘[R]apid assessment’ in its broadest sense – to denote those research approaches which aim to be cost-effective, timely, and inductively informed by a range of qualitative and quantitative methods to optimise validity – this ultimately only provides a description of the most basic features of such approaches . . .102

The public health research utilizing empirical evidence described above plays an important role in assessment of the ongoing response to the HIV epidemic (and indeed to all communicable disease) by elucidating the mechanisms through which law shapes health and health behaviors. However, traditional research protocols pose certain shortcomings when used to assess preparedness or response in the context of an emergency, epidemic, or some other type of disaster. Traditional research methods demand significant time and resources, and are therefore less useful where time is of the essence or resources are scarce.103 The differing methods that might be used to conduct a needs assessment of a particular population in various public health contexts illustrate this dilemma. For example, in a non-emergent setting, the ideal assessment method for an evaluation of the water system requirements in New York State could involve teams of researchers, input from stakeholders all over the state, mathematical modeling based on anticipated population growth and agricultural demands, as well as consideration of the possible impact of new technologies that might be in development. Such an assessment might take years and require millions of dollars before reaching any conclusions. By contrast, assessment of the needs of the public water system after a disaster such as the earthquake in Port au Prince, Haiti would, of necessity, be done quickly and with limited technological assistance. The primary goal of assessments in the context of emergencies is to provide enough accurate information to allow public health officials or humanitarian workers to respond quickly in ways that can save lives.104 Rapid assessment does not divided between New York and Illinois. Id. at 494. Data collected included their knowledge and beliefs about the law and their behavior. Id. at 492-93. The regression analysis conducted revealed no association between living in a state with or without an HIV-specific criminal law on the books and intention to either disclose one’s HIV status during the next sex act or use a condom, or between believing the law in the state prohibited unprotected sex, or failing to disclose one’s HIV positive status and the subjects’ subsequent intended behaviors. Id. at 491-92, 500-05.


103. Id. at 78.

take the place of traditional research in that it is not intended to provide answers that are equally reliable from a scientific perspective. 105 Rapid assessments use relatively small samples of data collected quickly using readily available sources and thus may be limited in scientific power and generalizability. 106 They can, however, provide guidance for beginning an immediate response that can be modified later as more complete data become available.

A. Early Rapid Assessment Tools

Rapid assessment technologies were developed specifically for use in low resource situations involving an epidemic, disaster, or emergency where conducting traditional needs assessments or research was not feasible, or would result in substantial morbidity, mortality, or further damage to important systems. 107 Rapid assessments are characterized by speed, use of multiple methods and sources of data, community involvement, "a cyclical process of inductive hypothesis formation and testing; and an investigative orientation familiar to aficionados of the detective novel." 108 Rapid assessments have been used to evaluate a wide range of public health problems including children’s nutritional status in poor areas, 109 as well as early applications within the AIDS epidemic. 110 Rapid Assessment and Response (RAR)—designed to identify and incorporate appropriate responses to locally identified problems—was refined in the context of the HIV epidemic by researchers who were originally from London’s Imperial College. 111 Although other researchers had published rapid assessment manuals, this team synthesized much of the work done by international organizations including the World Health Organization (WHO) and United Nations Drug Control Programme to produce the RAR model and specific

107. Id. at 65-66.
108. Id. at 66.
111. See Fitch, Rhodes & Stimson, supra note 102, at 72; Fitch et al., supra note 104, at 1819, 1823.
applications.\textsuperscript{112} Ultimately, the WHO published the Technical Guide to Rapid Assessment and Response (TG-RAR), a template that can be adapted to a variety of settings or health risks and provides all the guidance needed locally to plan and implement a rapid assessment and response.\textsuperscript{113}

The RAR, as originally developed, recognized the potential role of law and policy in many public health emergencies, and thus included questions related to the policy climate among its suggested queries.\textsuperscript{114} However, perhaps because there were no lawyers among the Imperial College group, law and policy were not a major focus of the data collection and no distinctions were made between different types or sources of law, or the particular roles of legal actors including police, militia, prosecutors, judges, or correctional facilities in the context of the local health problems.\textsuperscript{115} The RAR was intended primarily to assess health needs or health behaviors and focused on collecting other data, including legal data, only as they related to the target behavior or needs.\textsuperscript{116}

B. Development and Structure of a Rapid Assessment Focused on Law and Policy

In 2002, a team of U.S. researchers\textsuperscript{117} began work on a rapid assessment tool, based on the RAR model that would focus on the primary role of law and policy in shaping the conditions of health and disease, particularly of IDUs at risk of HIV.\textsuperscript{118} This approach treats law as both a

\begin{itemize}
\item \textsuperscript{112} See Fitch, Rhodes & Stimson, supra note 102, at 68-70.
\item \textsuperscript{114} See Fitch, Rhodes & Stimson, supra note 102, at 66.
\item \textsuperscript{115} See generally id. at 72 (discussing the early development of the guidelines for the Rapid Assessment Methodology and its focus, which did not include law or legal actors).
\item \textsuperscript{116} See Fitch et al., supra note 104, at 1821.
\item \textsuperscript{118} Zita Lazzarini et al., Rapid Assessment of Drug and Harm Reduction Policies in Eastern Europe and the Former Soviet Union, International Conference on AIDS (July 8, 2002), available at http://gateway.nlm.nih.gov/MeetingAbstracts/ma?f=102256920.html; Zita Lazzarini et al., Harm Reduction and Policy: A Resources Network for Eastern Europe and
Structural determinant of health and disease and as a potential avenue of intervention.

Rapid Policy Assessment and Response (RPAR) is a community-level action research intervention process that combines traditional legal research with qualitative research on implementation of laws, policies, and law enforcement practices. The original goals of the RPAR were to: (1) mobilize local knowledge to tackle complex health problems; (2) build capacity to make legal and policy interventions sustainable; and (3) alter the risk environment to reduce HIV transmission. Ultimately, with support from the National Institutes of Drug Abuse, the team developed the Rapid Policy Assessment and Response (RPAR) tools described below and applied them to situations involving rapid epidemic spread of HIV among marginalized populations in five countries.

1. Structure of the RPAR

The RPAR is designed to be useable by community groups or advocates with some legal assistance, or by public health and legal professionals in resource-poor settings. It combines traditional legal research to document “law on the books” – formal law in statutes, regulations, or ministerial decrees – with existing public health data, criminal justice statistics (where available) and qualitative interviews of key informants regarding the actual implementation of the law and law enforcement practices. The RPAR uses a Community Action Board to review and analyze the research findings using an analytical process based on nodal governance theory, and to work with the research team to translate the findings into an Action Plan. As with the RAR, the RPAR utilizes multiple resources...

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121. Partners and Participants, supra note 117. See supra note 6.
122. See History, supra note 117 (noting that projects have been launched in several countries, including Russia, Poland, Ukraine, China, Thailand, India, and Kazakhstan).
123. See What Is RPAR?, supra note 120.
124. See Overview, supra note 119.
126. See Overview, supra note 119.
sources of data but limited sample sizes.\textsuperscript{127} Although smaller samples make the conclusions of an RAR or RPAR less reliable or generalizable, the process increases the speed of the research and decreases the cost.\textsuperscript{128} Under epidemic or resource-limited conditions, some trade-offs between time and accuracy can be advantageous. The RPAR does not replace traditional research as much as it supplements it,\textsuperscript{129} giving public health officials a “jump start” on a response when to wait means possible increased morbidity and mortality.

The “inputs” or data for the RPAR include: (1) relevant law and policy – to identify and describe the legal structure in order to better understand practice; (2) epidemiological data on the health of the community – to identify both what is known about the populations’ particular disease risks and gaps in local surveillance; (3) law enforcement data, prosecutions, or other enforcement actions – to provide empirical evidence of policing or law enforcement efforts; and (4) qualitative data from interviews of key stakeholders and policy-makers and focus groups – to provide critical information on how the laws and policies are actually implemented by those most directly involved.\textsuperscript{130} In the case of an RPAR focusing on IDUs’ risk of HIV infection, key informants would include: police, prosecutors, judges, health care and public health officials, harm reduction and HIV advocacy groups (if they exist), as well drug users themselves.\textsuperscript{131} See Figure 2.

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\textsuperscript{127} See Kate MacIntyre, \textit{Rapid Assessment and Sample Surveys: Trade-Offs in Precision and Cost}, 14 \textit{HEALTH POL’Y & PLANNING} 363, 364 (1999) (noting that small sample size is an attribute of rapid survey assessments).
\textsuperscript{129} Fitch, Rhodes & Stimson, supra note 102, at 78.
\textsuperscript{130} See Overview, supra note 119.
\end{flushleft}
The RPAR was designed to be completed in nine months, from the beginning of training the research staff through the completion of the Action Plan and final report—considerably less time than a typical research project. The typical timeline of the RPAR is illustrated in Figure 3.

While the RPAR retains many critical structural similarities to the RAR and other rapid assessment technologies, it diverges significantly in its focus on legal problems and solutions. It also relies on analytic steps that are based on theories of governance and are more detailed than in the RAR.

2. Theoretical Basis for RPAR Analysis

The RPAR is deeply rooted in theories that link public health, law, sociology, social epidemiology, population-based legal analysis, and socio-legal and nodal governance theories. Public health researchers, seeking to explain differences in health across and between populations, have long suggested that research should focus more on causes of incidence (population measures of disease) rather than on causes of cases (individual measures of disease). Social epidemiology concentrates on the role of social determinants in health, emphasizing a structural approach to health that identifies population-based factors that influence health, in contrast to an individualized focus on personal behavior or exposure to specific pathogens. Population-based legal theory is closely related to social epidemiology in emphasizing the critical role of population-based or structural factors and identifying improved population health as a legitimate goal of law. Population-based legal theory differs from traditional legal scholarship's focus on formal law (“law on the books”) and emphasizes empirical methods that focus on how the law is actually implemented and how it influences population factors.

137. Id. at 2.
138. Id. at 53-54.
been described as a structural determinant of health and disease and one that can be studied, and even shaped, to promote better outcomes.\(^\text{139}\)

Recent public health scholarship has identified ways in which law and policy act as structural determinants of specific diseases or conditions,\(^\text{140}\) as well as how specific policies, such as drug policy, impact HIV.\(^\text{141}\) Another way of contextualizing law, socio-legal theory, suggests that laws and policies act in complex environments, and understanding law requires understanding the social context in which the law works.\(^\text{142}\) The social context of law includes what people believe about the law (legality) and how they act upon it—referred to by Silbey and others as "legal consciousness."\(^\text{143}\) For example, research suggests that the legal consciousness of law enforcement personnel, their beliefs about the law, and their resulting behaviors are key factors that shape injection drug users’ (IDUs’) risk environment.\(^\text{144}\)

Governance, or how to manage “the course of events in a system,”\(^\text{145}\) is critical to understanding and changing structural determinants of health, including how laws and policies are implemented. Efforts to change structural determinants of health, including implementation of laws and legal consciousness, often confront complex systems that are resistant to change, or which are controlled by powerful entities with little incentive to change. The theory of nodal governance ascribes this complexity to the increasingly decentralized distribution of power\(^\text{146}\) in social systems and the regulatory role often played by non-state actors.\(^\text{147}\)

\(^{139}\) Blankenship, Bray & Merson, supra note 135, at 512-13; Scott Burris, Ichiro Kawachi & Austin Sarat, Integrating Law and Social Epidemiology, 30 J.L. MED. & ETHICS 510, 510 (2002).


\(^{143}\) Id. at 8626.


\(^{145}\) Burris, Governance, supra note 125, at 336.

\(^{146}\) MICHEL FOUCAULT, THE HISTORY OF SEXUALITY, VOLUME 1: AN INTRODUCTION 92-93 (Vintage Books ed. 1990) (1978) (focusing on how power is part of a collective of social
Nodal governance uses “contemporary network theory [to explain] how a variety of actors operating within social systems interact along networks to govern systems they inhabit.”\textsuperscript{148} Nodal governance identifies the institutions with power, describes their relationships with one another, and identifies specific characteristics of the organizations (ways of thinking, methods of asserting influence, resources, and institutional structures) that affect how they influence outcomes in local systems.\textsuperscript{149} In practice, local actors can use the theory of nodal governance to map, assess, and re-shape systems to enhance “microgovernance” and population health.\textsuperscript{150} Nodal governance has been used as a conceptual framework for building local governance in South African townships,\textsuperscript{151} to explain the creation of the Trade Related Aspects of Intellectual Property Rights (TRIPS) agreement (a treaty establishing international intellectual property rules linked to the World Trade Organization),\textsuperscript{152} to investigate gang-related activity in Camden, New Jersey,\textsuperscript{153} and to describe the organizations in a Polish city that shape the lives of drug users.\textsuperscript{154}

Applied to HIV risk among IDUs, nodal governance theory would identify which actors in the community directly affect IDUs’ lives, how those organizations are connected to one another, and who wields the most influence over how they act. This could result in identifying people and institutions wielding great influence over IDUs that are not usually considered. Those individuals and organizations may well be critical to implementing effective HIV prevention for IDUs in that community. The RPAR process directly utilizes nodal governance theory to describe how power and influence work in the local community to influence IDUs’ daily lives and to identify how local public health advocates can shape the outcomes – in this case, IDUs’ ability and willingness to access HIV prevention, drug treatment, and other social services.
Social epidemiology, population-based legal analysis, socio-legal, and nodal governance theories provide a framework for using the empirical tools of RPAR to analyze how the law and policy environment influences public health efforts aimed at shaping the HIV risk environment for IDUs, reducing HIV transmission, and facilitating social re-integration of former IDUs into society.

3. Process of RPAR Analysis

Analysis in the RPAR begins early and continues throughout; revisiting some steps at each CAB and research team meeting. The specific steps or exercises included in the analysis section of the RPAR tools and their primary goals are illustrated in Figure 4.

Figure 4. Steps in the RPAR Analysis

In each city, the research team and the CAB draw on local knowledge to construct a “power map” of local individuals and institutions (“nodes”) that shape the lives of the target population, in this case IDUs. Nodes can be organizations, agencies, or affiliated actors that have both capacity and knowledge and that have the potential to interact with or influence other nodes.\(^{156}\) The power map is literally a visual representation of the nodes of power and influence over IDUs; each node is linked with arrows that indicate direction and strength of influence. Each node is characterized in terms of its mentality (ways of thinking), technologies (methods of asserting influence), resources available for its work, and institutional structures. The

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\(^{155}\) The RPAR process of analysis and the exercises included in this section were developed by the original RPAR team (Scott Burris, Zita Lazzarini, and Joe Welsh) and refined during the five-country study described herein (Zita Lazzarini, Principle Investigator; Scott Burris and Patricia Case, Co-Investigators; Repsina Chintalova-Dallas, Project Manager). The methods used rely on nodal governance theory, Burris, Drahos & Shearing, supra note 125, but the description of the analytical steps and their relationship to scientific applications outside of RPAR were developed by the author.

initial power map is saved and revised repeatedly during the analysis phase based on emerging knowledge from the research.

“Nodal governance is intended to enrich network theory by focusing attention on and bringing more clarity to the internal characteristic of nodes and thus to the analysis of how power is actually created and exercised within a social system.”157 The power map plays a key role in all stages of the analysis from identification of important actors (or those who are obviously missing), to inspiring possible solutions, prioritizing the most feasible interventions, and enlisting the actors critical to success. For example, in most U.S. cities, the probation department is a critical node affecting lives of drug users who have been convicted of drug-related crimes. Individual probation officers (POs) possess enormous amounts of local knowledge about persons in the community and institutions that drug users must interact with. POs’ actions are to a certain degree prescribed by law and policy within the department, but local leadership, as well as personal beliefs and motivation, play a role in how much and how effectively they interact with drug users on probation. Understanding how a PO applies the policies of the department may reveal facilitators or barriers to drug users accessing important HIV and drug treatment services, and ultimately, avoiding re-incarceration.

The CAB and research team also conduct the “problems and solutions exercise” repeatedly during the ongoing analysis process. This exercise is similar to those used in many settings, including industry,158 basic science laboratory management,159 and community health160 to generate novel ideas, encourage participation, and provide options for later critical evaluation. In the problems and solutions exercise the moderator asks each meeting participant to identify one problem and proposed solution within the general scope of issues discussed, encourages participation by everyone, limits questions to clarification, and defers discussion of the merits or relevance until another time. For example, a participant might suggest “Problem: drug users don’t buy syringes in pharmacies because pharmacists won’t sell to them, or, users believe the pharmacists will disclose the user’s

157. Burris, Governance, supra note 125, at 341.
160. Christian Dagenais et al., Knowledge Translation Research in Population Health: Establishing a Collaborative Research Agenda, 7 HEALTH RES. POL’Y & SYSTEMS 28, 30-31 (2009); Shane Scallill, Jeff Harrison & Peter Carswell, Describing the Organisational Culture of a Selection of Community Pharmacies Using a Tool Borrowed from Social Science, 32 PHARMACY WORLD & SCI. 73, 75 (2010).
identity to the police. Solution: educate pharmacists about the public health role of sterile syringes and the importance of confidentiality.” The moderator would ensure the suggestion was transcribed and understood, but defer discussion of the feasibility, expense, or priority of the proposal until a later stage. This process can spur creativity and reduce dominance by some group members, while enhancing participation, trust, and cooperation among diverse group members who may be from very different backgrounds.

The “root causes exercise,” requires the research team and CAB to use key findings from the legal analysis, criminal justice data, and qualitative interviews to assess the most important problems IDUs face and identify not just the proximate causes, but also the root causes of those problems. Called by various names, “cause analysis,” “root cause analysis,” or “cause mapping,” is a systems-level approach that helps people and institutions disaggregate factors contributing to any event, from medication errors, or unintended events in hospital emergency departments, to the causes of epidemics of hepatitis B and C in the U.S., or the financial meltdown of 2008-2009.

The RPAR “priority setting exercise” helps the team members determine which of the proposed interventions to include in the Action Plan. Proposed interventions may be sweeping (reduce racism in our city) or highly specific and practical (persuade the police not to harass IDUs entering or leaving the needle exchange). Priority setting processes have been used to allocate health care resources, create intra-organization strategic plans, contribute to Health Technology Assessments for coverage in government

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161. See Bazan, supra note 159, at 272-76.
programs, and even create clinical treatment plans for patients with complex co-morbidities. In the RPAR, the team evaluates the proposed interventions for: relevance (how important is it to lives of IDUs?); feasibility (what are the obstacles to its achievement and resources supporting its achievement?); and finally, assigns it a priority score or ranking. The RPAR tools provide both a quantitative scoring method and a “dot-voting” method for the group to choose from. Both mechanisms, although simple to administer, utilize clear criteria, give all participants a voice, and create a record of how the group made its decisions, thus promoting a transparent and evidence-based process.

Finally, the “power map action planning exercise” helps the research team and CAB decide how they will implement their proposed interventions and who will be responsible for doing so. Power map action planning utilizes the theory of nodal governance to suggest both strategies for change and to identify the “nodes” that can be used as pressure points to achieve the identified goals. Strategies include: how one organization (facilitator) may be able to influence another organization (target); ways to change the resources of an organization to help achieve its goal; ways to expand the tools (mechanisms of action an organization uses) available to an organization; or to change the mentality (attitudes or culture) of an organization. The first step of this process includes identifying particular individuals within each organization and how existing relationships and influence can persuade them to work towards the identified goal. This exercise also assists team members in the planning part of the process. Team members choose an individual or organization to take overall responsibility for each prioritized intervention, break the project down into discrete steps, set a time line for each step, and identify measurable indicators of success.

The results of the power map action planning are all the interventions to be included in the Action Plan, along with critical information for their implementation.
implementation and indicators for success. The CAB and research team can use the findings of the local study and Action Plan to achieve their goals in multiple ways. They may work directly with participating organizations and agencies on specific interventions, use the information generated to brief local and national law-makers, or hold community meetings or workshops as appropriate. Local teams can also use the specific interventions of the Action Plan as the basis for proposals seeking additional resources or grant funding.

C. Results of the RPAR or RPA in Four Countries

The U.S. researchers trained teams of local researchers consisting of four to six people in each country. The local research team organized the CAB, identified research subjects, collected all the data, and worked with the CAB on analysis and creating an Action Plan.

The RPAR was completed in three cities in countries across Eastern Europe and the Former Soviet Union: Szczecin, Poland; Odessa, Ukraine; and Kaliningrad, Russia. In Temirtau and Shymkent, Kazakhstan, the local teams conducted a modified version of the RPAR, the Rapid Policy Assessment (RPA), which piloted a simpler tool without the Community Action Board phase. RPARs have also been conducted in Kolkata, India by the original team of U.S. researchers, as well as in Thailand and China by groups trained by these researchers. This experience established that the RPAR and RPA were feasible, under a variety of local political conditions.

172. Team members listed by country: Poland: Justyna Sobeyko, Tatiana Duklas, Milosz Parczewski, Magda Leszczyszyn-Pynka, Piotr Bejnrowicz; Ukraine: Nataliya Kitesenko, Galina Kitesenko; Russia: Inna Vyshemirskaya, Alexander Koss, Victoria Ospenko, Olga Burkhanova; Kazakhstan: Nadezhda Kozachenko, Gulnara Darbekova, Irina Mingazova, Alexander Solodov, Natalia Kartashova.


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conditions and with relatively inexperienced local researcher teams.\textsuperscript{177} Through local Action Plans, the communities involved established new coalitions and organizations focused on HIV prevention,\textsuperscript{178} provided trainings for judges, conducted additional assessments in smaller municipalities,\textsuperscript{179} integrated education about harm reduction into a law school course,\textsuperscript{180} worked with former-IDUs on re-integration into society, and started harm reduction programs in prisons.\textsuperscript{181} The RPAR in Odessa identified evidence of an injected homemade amphetamine, Boltushka, which prompted U.S. and Ukrainian researchers to conduct additional research to describe its use and users.\textsuperscript{182} Additionally, several of the local researchers still working in the sites have applied for and received independent support of their initiatives from government, international, or foundation donors.

1. Summary of Findings

Researchers in each country produced a substantial volume of findings related to local practices of law enforcement, health care, militia, and/or the

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These findings focused on ways current practices either helped or hindered HIV prevention among injection drug users and other marginalized populations, such as sex workers or men who have sex with men. In each city, the CAB or local researchers implemented interventions to address local problems. These varied from working closely with the City government in Szczecin to incorporate the action plan into the City’s drug use prevention planning, to training social workers and health care workers about the benefits of harm reduction in Kaliningrad (where all harm reduction had been previously been stopped by local and national authorities). Additionally, local researchers generated three years of well-received abstracts and presentations at International Harm Reduction Association Conferences.

RPAR projects in the countries described identified locally important gaps in laws, their implementation or law enforcement practices, and leveraged their findings to prioritize community responses. Communities, researchers and CABs have used these priorities to guide action in a variety of ways. These include many changes that altered the HIV risk environment for IDUs and former IDUs.

2. RPAR Findings as Part of Assessment and Response

In addition to establishing that the RPAR process is feasible and can produce locally useful change, the project illustrates other uses of rapid assessment data. First, while in the process of looking for legal barriers to HIV prevention, researchers may find other, unexpected information – such as the discovery of new patterns of drug use (rural amphetamine use), new forms of a drug (Boltushka), or new risk behaviors. In such cases, rapid assessment raises additional research questions and identifies targets for early interventions. Additionally, rapid assessment data can be used to analyze patterns of findings across multiple jurisdictions or geographic areas. Here, the U.S. researchers analyzed findings across the sites to identify common problems. This multi-country analysis identified some issues common across most of the Eastern European and Former Soviet Union sites.

183. Final Reports for Poland, Russia, and Ukraine are available (in English) at RPAR website, Reports and Outcomes, TEMPLE U. BEASLEY SCH. OF L., http://www.temple.edu/law school/phrhcs/rpar/about/reports.html (last updated Feb. 2006). The Kazakh Final Report is not available at the time of this publication.


185. Vyshemirskaya et al., supra note 181.

186. See supra notes 173-74.
For example, the RPAR research provided ample evidence of the problems caused by the registration system for drug users; the continued use of “administrative offenses”; ongoing police coercion; and the legal and practical barriers to the social re-integration of drug users. The registration system for drug users was established as both a surveillance system under the old Soviet model and a means to regulate who had access to state-funded drug treatment services. Once registered (by a primary care physician, a narcologist, or the police) drug users would be eligible for state-funded services. However, in most states of the former Soviet Union, including Russia, methadone and other forms of opiate substitution therapy (OST) remain unavailable. Methadone and Buprenorphine have only recently been introduced in Ukraine. In the absence of OST, drug treatment might mean confinement and detoxification with minimal medical or behavioral interventions. The legal consequences of registration, however, include loss of driver’s license, passport, and the inability to work in many types of jobs. One RPAR respondent described the consequences of registration this way:

“[IDUs are afraid of registration] . . . Because you instantly lose all the privileges and potentials that you might gain in the future.” (IDU, male, 30 y.o., Russia)

Registration provisions have no “sunset clause”, periodic review, or natural end. While the law does provide mechanisms to remove one’s name from the registration list, these are not well understood by former IDUs or many of those who work with them. In Russia, the process requires former users to appear before officials periodically throughout a lengthy (five year) period before they can become “unregistered.” One former IDU described it as follows,

“[I have not gotten out of registration] . . . Because it’s really difficult. You need to go there every month. I told them that I haven’t shot anything in five years. So I came there – take me out registry. And they tell me: ‘you were supposed to be coming here this entire five years. . .’” (Russia-NGO staff and former IDU working with HIV+ people, male, 38 y.o.)

In Odessa and Kaliningrad, no one had ever tried to help former drug users remove their names from the registration lists. The Action Plan in Kaliningrad included establishing and supporting the organization of a self-

help group of former users, who worked their way through the process of removing their names from the registration system and thereby taking one step towards returning to more productive lives.189

In the case of drug user registration, the common problems identified across several of the sites appeared to be susceptible to legal and policy interventions that would have a significant effect on the vulnerability of populations at risk for HIV, particularly IDUs, their partners, and children.190 Implementing those changes were outside the scope of the RPAR itself, but the evidence supporting the changes will be used on the local, national, and international level in the ongoing debate about the best ways to prevent HIV infection among IDUs.191

Based on nearly thirty years of experience with HIV/AIDS, we know what laws and policies make up “best practices” for jurisdictions seeking to prevent the spread of HIV among drug users192 and to protect those with HIV from discrimination or other harms. We do not need more large-scale studies to answer the big policy questions. We need the political will within countries and localities to act and make the right choices based on those best practices. Until that time, we can use implementation-based studies, such as rapid assessments, to identify local problems, mobilize the community, and either change law and policy barriers or devise ways to “work with” or “work around” policies that may be difficult to change.

CONCLUSION

Assessment before, during, and after an emergency or epidemic can provide critical information about gaps in the laws, unused provisions within the law, and practice patterns that may frustrate the stated purposes of the law. As such, they can form the basis for local action, building new community networks, additional research, national and regional policy-change initiatives, and advocacy at every level to make public health policy more effective. However, neither rapid assessments nor more traditional research are sufficient absent the political will to invest in evidence-based public health policies.

189. See Vyshemirskaya et al., supra note 181.
190. See Lazzarini et al., supra note 187.
192. See David Vlahov, Angela M. Robertson & Steffanie A. Strathdee, Prevention of HIV Infection Among Injection Drug Users in Resource-Limited Settings, 50 CLIN. INFECTIOUS DISEASES S114, S114 (2010); Evan Wood et al., Vienna Declaration: A Call for Evidence-Based Drug Policies, 376 LANCET 310, 310-12 (2010).