

THE ETHICS OF CONTACT TRACING PROGRAMS AND THEIR IMPLICATIONS FOR WOMEN

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I. INTRODUCTION

Partner notification and contact tracing are well-established public health interventions designed to reduce the incidence of new cases of sexually transmitted diseases.¹ The idea behind such programs is to inform the sexual and drug-using contacts of infected patients of their potential exposure so that the chain of infection can be broken.² After researchers discovered that HIV could be transmitted sexually, there were calls to implement partner notification and/or contact tracing programs as public health interventions.³ While there have been several analyses of whether partner notification programs are appro-

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1. See Larry Gostin, *Traditional Public Health Strategies*, in *AIDS AND THE LAW: A GUIDE FOR THE PUBLIC* 47, 54-58 (Harlon L. Dalton et al. eds., 1987) (discussing case identification through screening and contact tracing); see also ALLAN M. BRANDT, *NO MAGIC BULLET: A SOCIAL HISTORY OF VENEREAL DISEASE IN THE UNITED STATES SINCE 1880* 150-52 (1985) (describing contact epidemiology as a traditional approach to communicable disease, and documenting how contact tracing became part of the war on syphilis beginning in the 1930s); INSTITUTE OF MED., NATIONAL ACADEMY OF SCIENCES, *CONFRONTING AIDS: UPDATE 1988* 81 (1988) (describing venereal disease statutes in many states that give public health officials the power or duty to inquire about a person's previous and current sexual partners).

2. See BRANDT, *supra* note 1, at 150; see also INSTITUTE OF MED., *supra* note 1, at 82 (postulating that voluntary contact notification programs can be useful in preventing the spread of HIV).

3. See, e.g., Donald P. Francis & James Chin, *The Prevention of Acquired Immunodeficiency Syndrome in the United States: An Objective Strategy for Medicine, Public Health, Business, and the Community*, 257 *JAMA* 1357, 1361 (1987) (stating that contact tracing and partner notification will help to provide "appropriate education and motivation of the infected and susceptible contacts, [in order that] further transmission can be prevented").

priate public health policy for HIV/AIDS,⁴ few have focused specifically on the effects, both good and bad, that such programs have on women.

This Article analyzes HIV partner notification programs, giving special emphasis to their gender implications. Part II of this Article describes different types of partner notification programs, focusing on contact tracing programs. Contact tracing programs constitute the typical manner in which partner notification interfaces with public policy; the state must decide whether it will implement this sort of program as a public health intervention. By contrast, the other types of partner notification programs, provider referral and patient referral notification, likely will continue to be implemented in private by individual doctors. Part III of the Article examines contact tracing through the lens of bioethics, introducing three principles of bioethics—beneficence, respect for autonomy, and justice⁵—and how contact tracing would be viewed in light of these principles. It is important to remember, however, that while each principle should be satisfied on its own, there are times when satisfying one necessarily means compromising another.⁶ In such cases, the principles must be weighed in terms of their importance.⁷ This Article examines the extent to which contact tracing programs satisfy these principles generally, and then addresses the extent to which they satisfy the principles specifically for women. Finally, Part IV provides recommendations for public health policy.

II. PARTNER NOTIFICATION PROGRAMS

Partner notification programs identify and inform the sexual and/or drug-using partners of a patient identified with an infectious disease.⁸ Contact tracing programs are a mainstay of public health, having been used historically to help contain the spread of many other sexually transmitted diseases (STDs),⁹ and they can be implemented in several ways. Contact tracing programs are carried out by public health departments or the patient's own doctors.¹⁰ Typically, doctors report the names of individuals infected with legally reportable STDs to the

4. See, e.g., Ronald Bayer & Kathleen E. Toomey, *Health Law and Ethics: HIV Prevention and the Two Faces of Partner Notification*, 82 AM. J. PUB. HEALTH 1158, 1159-60 (1992) (describing the history of different approaches to partner notification and the ethical dilemmas inherent to each).

5. These principles were articulated in NATIONAL COMM'N FOR THE PROTECTION OF HUMAN SUBJECTS OF BIOMEDICAL & BEHAVIORAL RESEARCH, THE BELMONT REPORT: ETHICAL PRINCIPLES AND GUIDELINES FOR THE PROTECTION OF HUMAN SUBJECTS OF RESEARCH 4 (1979); see also TOM L. BEAUCHAMP & JAMES F. CHILDRESS, PRINCIPLES OF BIOMEDICAL ETHICS 58, 170-73 (3d ed. 1983) (discussing these bioethical principles).

6. See TOM L. BEAUCHAMP & JAMES F. CHILDRESS, PRINCIPLES OF BIOMEDICAL ETHICS 105 (4th ed. 1994) ("[W]e treat principles as both prima facie binding and subject to revision. . . . The latitude to balance principles in cases of conflict leaves room for compromise, mediation, and negotiation.").

7. See BEAUCHAMP & CHILDRESS, *supra* note 5, at 128 ("[T]here must be proportionality or a favorable balance between the good and bad effects of the action.").

8. See Francis & Chin, *supra* note 3, at 1361.

9. See BRANDT, *supra* note 1, at 151; see also Jon K. Andrus et al., *Partner Notification: Can It Control Epidemic Syphilis?*, 112 ANNALS INTERNAL MED. 539, 542 (1990) (describing sex-partner notification in the control of syphilis).

10. See INSTITUTE OF MED., *supra* note 1, at 81.

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public health department.¹¹ The public health department then contacts the infected individuals and asks them to provide the names of all sexual or drug contacts they have had over a given period of time;¹² all of the persons named are contacted by the public health department and are informed that they might have been exposed to the disease at issue.¹³ While some states require the reporting of HIV/AIDS infection, and some of those have contact tracing or partner notification programs, no state allows the unwilling disclosure to contacts of the name of the original patient who had provided the contact's name.¹⁴ Contacts are encouraged to be tested for the disease themselves, and those found to be infected are asked to provide names of their contacts, who are informed of their potential exposure to the disease and are offered testing.¹⁵ The process continues until all contacts are notified and have been counseled about testing and risk reduction. Public health departments are expected to be non-judgmental in their execution of contact tracing by focusing on the goal of preventing the further spread of infectious disease.

The two main partner notification techniques are provider referral and patient referral programs.¹⁶ In provider referral programs, patients' own doctors notify the contacts;¹⁷ they ask patients the names of their contacts, and, only with the patient's knowledge and permission, inform the contacts that they have been exposed to an infectious disease, never identifying the source patient by name.¹⁸ By contrast, patient referral means that after a patient is found to have an infectious disease, the patient is asked by doctors to inform all of her partners herself.¹⁹ In some instances, counseling is provided to help patients learn how to carry out this sometimes difficult or awkward task.²⁰

11. See MARTIN GUNDERSON ET AL., AIDS: TESTING AND PRIVACY 141 (2 Ethics in a Changing World, 1989) (observing that reporting laws "facilitate contact tracing" and that reporting laws and contact tracing by public health departments relieve physicians of the dilemma of whether to break patient confidentiality).

12. See INSTITUTE OF MED., *supra* note 1, at 81.

13. See *id.*

14. See GUNDERSON ET AL., *supra* note 11, at 141 (stating that "all states with such [contact tracing] programs protect the confidentiality of the infected person").

15. See Bayer & Toomey, *supra* note 4, at 1159 (explaining the scope of partner notification as originally envisioned in 1936).

16. See *id.* at 1160; see also James T. Dimas & Jordan H. Richland, *Partner Notification and HIV Infection: Misconceptions and Recommendations*, 4 AIDS & PUB. POL'Y J. 206, 206 (1989) (stating that the contact tracing alternatives are "patient referral and provider referral. Under the patient referral model . . . health care providers encourage index patients to notify their partners directly Using [provider referral], the . . . health care provider is responsible for notifying partners that they may have been exposed to HIV.").

17. See Dimas & Richland, *supra* note 16, at 206.

18. See Bayer & Toomey, *supra* note 4, at 1158. The paradigmatic case of provider referral is the doctor who informs the unsuspecting wife of a bisexual man that her husband is HIV-infected and that she is at risk. See *id.* at 1161.

19. See Kathleen E. Toomey & Willard Cates Jr., *Partner Notification for the Prevention of HIV Infection*, 3 AIDS S57, S57 (1989 Supp. 1).

20. See *id.*

III. THREE PRINCIPLES OF BIOETHICS

A. Beneficence

The first principle, beneficence, means that persons have the responsibility to do good for others, to prevent harm to others, or, at the very least, to avoid directly harming others.²¹ Beneficence also requires the balancing of harms and benefits that might result from a given policy to determine whether or not, on balance, the policy is beneficial.²² It is out of beneficence that contact tracing (or any other public health program) would be suggested. The goal of contact tracing programs is to prevent additional cases of HIV, and this unquestionably is a goal with good, or "beneficent," intent. The next relevant questions, then, are how effective contact tracing programs are in achieving this goal, and whether there are negative consequences also associated with contact tracing programs. That is, to what extent do contact tracing programs satisfy the principle of beneficence?

This Article attempts to establish that for a contact tracing program to be effective in preventing new cases of infection, all five of the following assumptions must be satisfied: 1) the index patients must know and be willing to disclose the names of their contacts, and it must be possible to locate the contacts; 2) a significant proportion of the persons contacted must not have known already that they had been exposed to HIV, and they must have been practicing unsafe practices before and be willing to change to safer practices now; 3) a significant proportion of the persons contacted must be willing to be tested; 4) some number of those found to be HIV-infected will not have known already that they were infected; and 5) some number of persons found to be HIV-infected must have been practicing unsafe practices before being contacted who will change to safer practices after being informed of their potential exposure.

The extent to which these assumptions have been met in the case of contact tracing for HIV is unknown, largely because there are few published studies evaluating contact tracing programs in those terms. The studies that have been conducted typically reported health department efforts to trace the contacts of a single infected person.²³ Several studies and commentators suggest that, given the expense, contact tracing programs reach the zenith of their appropriateness in relatively low-risk settings, perhaps where an individual might not suspect that he or she was exposed to the infection, or where numbers of contacts are

21. See Tom L. Beauchamp & LeRoy Walters, *Ethical Theory and Bioethics*, in CONTEMPORARY ISSUES IN BIOETHICS 1, 30 (Tom L. Beauchamp & LeRoy Walters eds., 4th ed. 1994).

22. See *id.* at 32.

23. See, e.g., K. Waldron et al., *Notification of Syringe-Sharing and Sex Partners of HIV-Infected Persons—Pennsylvania, 1993-1994*, 44 MORBIDITY & MORTALITY WKLY. REP. 202, 202-03 (1995) (describing the contact tracing of drug and sexual partners of one HIV-infected man in prison in Pennsylvania: "follow-up of the four partners of the index patient and all subsequently identified partners of HIV-infected persons identified a social network of 124 persons linked by syringe-sharing and/or sex . . . [Staff spend 2 ½ to 10 hours locating and interviewing each contact. The estimated cost . . . for partner notification of this network was \$13,969."); Randolph F. Wykoff et al., *Contact Tracing to Identify Human Immunodeficiency Virus Infection in a Rural Community*, 259 JAMA 3563, 3564 (1988) [hereinafter Wykoff et al., *Contact Tracing*] (describing a rural South Carolina contact investigation tracing 83 sexual contacts of HIV-positive men).

small.²⁴ In high risk settings, by contrast, it has been suggested that all persons should be encouraged to seek testing, rather than just those identified through a contact tracing program.²⁵ Indeed, while contact tracing has been feasible (that is, contacts could be located) in many settings, it is virtually impossible in others. One study examined sexually transmitted disease contact tracing in Oregon.²⁶ Investigators found that contact tracing was an effective disease control mechanism for gonorrhea but not for syphilis.²⁷ They attributed the difference in effectiveness, first, to the fact that the period in which one can be infectious is much longer with syphilis²⁸ and therefore someone with syphilis could have infected many more partners during that time. Second, people with syphilis were more likely than people with gonorrhea to have had anonymous sexual partners who therefore could not be named.²⁹ It generally will be more difficult to name and locate partners in settings where individuals have had multiple and/or anonymous partners, and in settings where drug use plays a major role.³⁰ For example, a study of heterosexual partners of persons with AIDS (PWAs) in San Francisco (a city considered to include many persons at high risk for AIDS) reported that fifty-six percent of the contacts that investigators had attempted to locate either had died, had refused to participate, or had moved out of town.³¹ Indeed, the resource-intensity of contact tracing programs typically makes them impractical on a large scale.³²

24. See Andrus et al., *supra* note 9, at 542 (reporting that those afflicted with gonorrhea had fewer and more easily-identifiable sexual partners and implying that contact tracing would be better suited as a prevention mechanism among gonorrhea, as opposed to syphilis, sufferers); Francis & Chin, *supra* note 3, at 1361.

25. See Francis & Chin, *supra* note 3, at 1361.

26. See generally Andrus et al., *supra* note 9, at 539, 542-43 (evaluating why the same infection control measures with both syphilis and gonorrhea in the state of Oregon resulted in no change in gonorrhea rates but a 159% increase in syphilis). The study concluded that “[b]ecause patients infected with syphilis have relatively large numbers of anonymous sexual encounters, prevention strategies that supplement partner notification are urgently needed to control the syphilis epidemic among adults.” *Id.* at 539.

27. See *id.* at 541-42.

28. See *id.* The researchers also observed that “because syphilis has a longer infectious period than gonorrhea, patients with syphilis are more likely to have a greater number of partners from further in the past” *Id.* at 542. HIV also has a lengthy incubation period. See Allan M. Brandt, *Sexually Transmitted Disease: Shadow on the Land, Revisited*, 112 ANNALS INTERNAL MED. 481, 482 (1990) (noting that “[s]tate-mandated partner notification appears unlikely to effect positively the course of the HIV epidemic [T]he long period of infectiousness of HIV as well as the current inability to render persons noninfectious further diminishes the potential advantages of tracing contacts”); George W. Rutherford et al., *Partner Notification and the Control of Human Immunodeficiency Virus Infection: Two Years of Experience in San Francisco*, 18 SEXUALLY TRANSMITTED DISEASES 107, 109 (1991).

29. See Andrus et al., *supra* note 9, at 542.

30. See Toomey & Cates, *supra* note 19, at S59.

31. See Rutherford et al., *supra* note 28, at 108.

32. See Gostin, *supra* note 1, at 57 (observing that “contact tracing requires . . . a fair investment of time; it is ill-suited for use on a large scale [M]andatory contact tracing . . . with the attendant threats to confidentiality and the sheer numbers involved, is impractical.”).

Another study in rural South Carolina followed the contact tracing process for 25 index patients.³³ The index patients named 207 partners who resided locally, and 202 of them agreed to counseling and testing.³⁴ About one-third of those found to be infected previously had suspected that they might have been exposed to HIV.³⁵ Seventy-seven percent of contacts said that the contact tracing program had been helpful, while seven percent said it had been harmful, mostly because of the depression they experienced once they learned that they might have been exposed to HIV.³⁶ A different report based on this same study found that both HIV-positive and HIV-negative partners increased condom use from none to eighty percent and sixty-nine percent, respectively, after being contacted.³⁷

In the San Francisco study,³⁸ 51 HIV-positive index patients who were reported to the health department identified 135 opposite-sex sexual partners in the preceding five years.³⁹ The 59 partners contacted by the study were interviewed and offered testing.⁴⁰ Compared to index patients, the partners were more likely to be women and to be younger.⁴¹ Of these partners, 26 women agreed to be tested and 3 (twelve percent) were found to be positive, compared to 6 men who agreed to be tested and 4 (sixty-seven percent) were found to be positive.⁴²

The South Carolina study examined 84 female and 401 male sexual and needle-sharing partners of HIV-infected individuals.⁴³ Investigators found that sixty-three percent of the females and fifty-seven percent of males agreed to be tested for HIV, with twenty-one percent of the women testing positive, as compared to seventeen percent of the men.⁴⁴ For 36 HIV-positive participants who were re-interviewed at least once during the six to twenty-four month follow-up period, the number of named contacts decreased eighty percent from a mean of 5.6 to 1.1.⁴⁵ For 101 HIV-negative participants who were re-interviewed, there was a fifty percent decrease in number of named contacts, from 4.0 to 2.0.⁴⁶ These latter results were not analyzed separately by gender.

Several studies have examined the impact of contact tracing programs specifically on women. One study conducted in Mexico suggested that contact

33. See Jeffrey L. Jones et al., *Partner Acceptance of Health Department Notification of HIV Exposure, South Carolina*, 264 JAMA 1284, 1285 (1990).

34. See *id.*

35. See *id.*

36. See *id.*

37. See Wykoff et al., *Contact Tracing*, *supra* note 23, at 3566.

38. See Rutherford et al., *supra* note 28, at 107.

39. See *id.* at 108.

40. See *id.*

41. See *id.*

42. See *id.*

43. See Randolph F. Wykoff et al., *Notification of the Sex and Needle-Sharing Partners of Individuals with Human Immunodeficiency Virus in Rural South Carolina: 30-Month Experience*, 18 SEXUALLY TRANSMITTED DISEASES 217, 219 (1991).

44. See *id.* at 219.

45. See *id.* at 220.

46. See *id.*

tracing programs can be beneficial particularly to women;⁴⁷ this result likely follows from the fact that women are significantly less likely than men to know they are at risk of contracting HIV. In this study, some women were notified that their male partners had HIV and other women were not.⁴⁸ The women who were notified were significantly more likely to modify their sexual behavior and to avoid intercourse than the women who had not been notified.⁴⁹ The epidemiological literature reveals that women who are infected via sexual contact with infected male partners are a growing proportion of the HIV-infected population.⁵⁰ For some women, their only risk factor is the behavior of a male partner with whom they are monogamous.⁵¹ Not knowing that they may be at risk, many women do not seek testing until "the discovery of a partner's risk [or] disclosure of risk."⁵²

These studies suggest that persons who are informed by contact tracing programs that they might have been exposed to HIV generally are grateful to have been informed, and a sizeable portion did not know that they might have been exposed. A sizeable proportion then report that they started to use condoms when previously they had not.

B. Respect for Autonomy

The second principle, respect for autonomy, means that people must be respected as autonomous agents who have the right to make decisions for themselves without interference from others.⁵³ It is this principle that creates a moral right to privacy and, in turn, a right to decide whether, when, and to whom to release personal information.⁵⁴ In the medical profession, there is a lengthy history of maintaining confidentiality in the doctor-patient relationship.⁵⁵ Concerns

47. See WOMEN AND HIV/AIDS: AN INTERNATIONAL RESOURCE BOOK 233 (Marge Berer & Sunanda Ray eds., 1993).

48. See *id.*

49. See *id.*

50. See, e.g., CENTERS FOR DISEASE CONTROL & PREVENTION, U.S. DEP'T OF HEALTH & HUMAN SERVS., NO. 1, HIV/AIDS SURVEILLANCE REPORT 8 tbl.3 (1997) (showing that women increasingly are constituting a greater proportion of AIDS cases); Tedd V. Ellerbrock et al., *Heterosexually Transmitted Human Immunodeficiency Virus Infection Among Pregnant Women in a Rural Florida Community*, 327 NEW ENG. J. MED. 1704, 1704 (1992) (finding that "[i]n the United States, women account for an increasing number and percentage of the cases of the acquired immunodeficiency syndrome (AIDS) among adults").

51. See Lorraine Sherr, *Psychosocial Aspects of Providing Care for Women with HIV Infection*, in HIV INFECTION IN WOMEN 107, 108 (Howard Minkoff et al. eds., 1995).

52. Dooley Worth, *Women at High Risk of HIV Infection: Behavioral, Prevention, and Intervention Aspects*, in BEHAVIORAL ASPECTS OF AIDS 101, 102 (David G. Ostrow ed., 1990).

53. See Beauchamp & Walters, *supra* note 21, at 28-29.

54. See BEAUCHAMP & CHILDRESS, *supra* note 5, at 319; see also generally Scott Burris, *Testing, Disclosure, and the Right to Privacy*, in AIDS LAW TODAY: A NEW GUIDE FOR THE PUBLIC 115, 131-34 (Scott Burris et al. eds., 2d ed. 1993) (discussing in great detail confidentiality, privacy, and limits to privacy).

55. See Richard Belitsky & Robert A. Solomon, *Doctors and Patients: Responsibilities in a Confidential Relationship*, in AIDS AND THE LAW, *supra* note 1, at 201, 201 (describing the tension between the duty to disclose in order to protect third parties and the responsibility to safeguard the patient's confidentiality within a context in which "[p]hysicians have long considered the duty to safeguard a patient's confidences a paramount concern").

about invading privacy and maintaining confidentiality historically have led to the harshest criticisms of contact tracing programs.⁵⁶ Strictly speaking, privacy can be preserved by individuals' simply choosing not to disclose their partners' names.⁵⁷ It is not clear, however, how well individuals understand that when a public health department official asks them to provide a name, they will not be penalized for refusing to comply. That is, while public health officials ask individuals to comply by providing the names of their contacts, there is no penalty for refusing. If individuals are not aware of this, they potentially provide names against their will or better judgment. Indeed, it may be true that individuals who are more sophisticated about their rights will be less likely to comply with contact tracing programs, while those who are less sophisticated will believe that they have no choice. In addition, although public health officials are never required to reveal individuals' identities⁵⁸ and have a strong record of preserving confidentiality,⁵⁹ some contacts, especially those who have had only one sex or needle-sharing partner, would have little difficulty deducing the identity of the original patient who had provided his or her name. Moreover, contacts are under no similar mandate to maintain confidentiality. If a contact knows the index patient's name, there is nothing to stop the contact from disclosing the index patient's name and HIV infection status to others. Generally, the greater the number of people who have confidential information, the greater the likelihood that there will be an unauthorized release.

The possibility that the contact will know the identity of the index patient is of particular concern to women as index patients, for whom the consequences of disclosure may be particularly severe.⁶⁰ Women may choose not to disclose that they are HIV-positive because they fear losing their children,⁶¹ they distrust service agencies,⁶² or they fear being stigmatized.⁶³ Results from qualitative in-

56. See, e.g., Brandt, *supra* note 28, at 481-82 (observing that, although partner notification has been considered "an important element of public health policy to control epidemic disease," it has "rarely been systematically evaluated," and emphasizing that individuals need to be found who can be brought into care, yet "[t]o ask persons to voluntarily name contacts when neither the index patient nor the partner are adequately protected from discrimination or assured of adequate services will lead to suspicion and justifiable skepticism among those at greatest risk"); Lawrence O. Gostin et al., *The Case Against Compulsory Casefinding in Controlling AIDS—Testing, Screening and Reporting*, 12 AM. J. L. & MED. 7, 19, 23-24, 46 (1987) (stating that compulsory screening engenders personal costs, including restricting individuals' right to privacy and to control access to personal information, and that these personal costs are likely to outweigh any public benefit).

57. See Bayer & Toomey, *supra* note 4, at 1158 ("[Contact tracing] was formally predicated upon the voluntary cooperation of the patient in providing the names of contacts . . .").

58. See *id.*

59. See INSTITUTE OF MED., *supra* note 1, at 81.

60. See Karen H. Rothenberg & Stephen J. Paskey, *The Risk of Domestic Violence and Women with HIV Infection: Implications for Partner Notification, Public Policy, and the Law*, 85 AM. J. PUB. HEALTH 1569, 1570 (1995) ("Forty-five percent of all providers surveyed had at least one female patient who expressed fear of physical violence resulting from disclosure of her diagnosis to a partner, while 56% of providers had patients who expressed fear of emotional abuse and 66% had patients who expressed fear of abandonment.").

61. See Michael Pizzi, *Women, HIV Infection, and AIDS: Tapestries of Life, Death, and Empowerment*, 46 AM. J. OCCUPATIONAL THERAPY 1021, 1022 (1992).

62. See *id.*

interviews with fifty HIV-infected women echo some of these themes: two-thirds of the women interviewed were afraid to tell others of their infection because they feared rejection, violence, discrimination, and public ignorance of the disease.⁶⁴ These women expressed concern that their infection would become “general knowledge” and feared negative social consequences if others knew that they were HIV-infected.⁶⁵ For example, a man was rumored to have been killed when his neighbors learned he was ill,⁶⁶ a woman was assaulted on the street when others in her neighborhood heard that she was infected.⁶⁷

These examples illustrate that maintaining confidentiality is a critical concern, and difficult to ensure. Disclosing to their male partner was difficult for some of the women in this study and two (four percent) did not tell their partners out of fear of violence.⁶⁸ Even when women voluntarily disclose their status, there is evidence that negative consequences may ensue. In a study of 257 HIV-infected women, adverse social and physical consequences of living with HIV, such as being rejected by partners, family members, and friends, or being verbally, sexually, or physically assaulted, were examined.⁶⁹ Virtually all of the women in this study had disclosed their status to others,⁷⁰ and forty-four percent reported experiencing negative consequences.⁷¹ Moreover, as the number of people to whom the women disclosed their status increased, their risk of experiencing negative consequences increased.⁷²

Policies such as contact tracing, therefore, in which individual autonomy inevitably is compromised, should factor in the known risks of harm when such data are available. As more is learned about the consequences of disclosure for women, contact tracing programs should use this information to build in necessary safeguards.

63. See, e.g., Gill Green, *Attitudes Towards People with HIV: Are They As Stigmatizing As People with HIV Perceive Them To Be?*, 41 SOC. SCI. MED. 557, 557 (1995) (stating that people with HIV are “doubly-stigmatized” because they have a fatal, infectious disease that is prevalent especially among gay men and drug users who are already subject to prejudice—they are seen as dangerous to others because the disease is contagious, and because they are blamed for their condition); Andrea Carlson Gielen et al., *Women’s Disclosure of HIV Status: Experiences of Mistreatment and Violence in an Urban Setting*, WOMEN & HEALTH, Vol. 25, No. 3, 1997, at 19, 25-28 (discussing concerns raised by HIV-positive women when asked about their personal experiences with disclosure) [hereinafter Gielen et al., *Women’s Disclosure*].

64. See Gielen et al., *Women’s Disclosure*, supra note 63, at 25.

65. See *id.*

66. See *id.* at 26.

67. See *id.* at 27.

68. See *id.* at 26.

69. See Andrea Carlson Gielen et al., *Women Living with HIV: Disclosure, Violence and Social Support 6-7* (1997) (unpublished manuscript on file with the *Duke Journal of Gender Law & Policy*). [hereinafter Gielen et al., *Women Living with HIV*].

70. See *id.* at 5.

71. See *id.* at 6.

72. See *id.* at 7.

C. Justice

The third principle, justice, requires that people be treated fairly;⁷³ restrictions cannot be imposed on, or benefits provided to, one person or one group of people when another similarly-situated person or group is treated differently without adequate justification.⁷⁴ In the context of public policy, this means that a policy cannot disproportionately impact, either favorably or unfavorably, any particular subpopulation without appropriate justification, and the implementation or execution of the policy must be fair.⁷⁵ For example, a contact tracing program cannot trace only the contacts of homosexuals, or only for the contacts of Medicaid patients, unless there is sound scientific justification. One study suggests that contact tracing policies indeed are not implemented fairly; doctors surveyed indicated that variables such as gender, race, and sexual orientation would influence a decision to maintain or to violate patient confidentiality.⁷⁶ In this study, physicians were given case descriptions of hypothetical HIV-infected patients whose identities were altered in terms of their race, gender, and sexual preference, while all other aspects of the case remained identical.⁷⁷ In the small study sample, physicians were five times more likely to violate patient confidentiality when the patient was a black, heterosexual male than when the patient was a black, homosexual female.⁷⁸ These findings suggest that physicians may execute their responsibilities with regard to contact tracing inconsistently depending on the demographics of their HIV-infected patients.

A broader justice question, and of particular relevance to women, is whether contact tracing programs have differential impact on diverse groups in terms of the harms or benefits they impart. While contact tracing programs may be beneficial for women who are HIV-negative, such programs potentially are harmful for HIV-positive women.⁷⁹ As described above, women are at greatest risk for contracting HIV when they are unaware that their male partners are infected. Given that contact tracing programs are designed expressly to inform contacts who might otherwise be unaware of their potential exposure, uninfected women stand to benefit from the implementation of contact tracing programs. Since women are at greater risk of heterosexual transmission than are men,⁸⁰ it stands to reason that heterosexual women are more likely than heterosexual men to benefit from contact tracing. While a disproportionate benefit often indicates that a proposed program is unjust, the disproportionate benefit is

73. See Beauchamp & Walters, *supra* note 21, at 32.

74. See *id.* at 33.

75. See *id.*

76. See Judith A. Schwartzbaum et al., *Physician Breach of Patient Confidentiality Among Individuals with Human Immunodeficiency Virus (HIV) Infection: Patterns of Decision*, 80 AM. J. PUB. HEALTH 829, 833 (1990).

77. See *id.* at 829.

78. See *id.* at 830.

79. See INSTITUTE OF MED., *supra* note 1, at 82; Rothenberg & Paskey, *supra* note 60, at 1571.

80. See CENTERS FOR DISEASE CONTROL & PREVENTION, U.S. DEP'T OF HEALTH & HUMAN SERVS., NO. 2, HIV/AIDS SURVEILLANCE REPORT 10 tbl.3 (1996).

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not unjust if there also is a disproportionate need or risk,⁸¹ as there seems to be for HIV-negative women.⁸²

For the smaller (compared with HIV-negative) but nonetheless significant proportion of women who are HIV-positive, however, contact tracing can pose serious risks to their safety if a male partner becomes violent after being informed of the woman's status.⁸³ This fear of violence is a concern with contact tracing that appears to impact women disproportionately.⁸⁴ Juxtaposing anecdotal reports of women being assaulted or killed as a result of being identified as HIV-positive⁸⁵ with what is known about the prevalence of domestic violence more generally,⁸⁶ difficult questions are raised about balancing the potential public health benefits of contact tracing with the risks of the tracing to women. Physical and sexual assault of women is not uncommon; recent national surveys indicate that approximately twelve percent of women reported being physically assaulted by an intimate male partner at least once in the previous year, and physical violence occurs in twenty-eight percent of all marriages in the United States.⁸⁷ Violence in interpersonal relationships poses more risk to women than to men;⁸⁸ women are at greater risk than men for intimate partner violence that results in serious injury or death.⁸⁹

Studies of women whose sociodemographic characteristics are similar to those of women at greatest risk for HIV (that is, minority women living in low-income, urban areas) have found that as many as thirty-four percent of women report having experienced domestic violence.⁹⁰ Sexual assault typically is not included in measures of domestic violence, but lifetime prevalence estimates of sexual assault are generally at about twenty percent.⁹¹ In a sample of 257 HIV-positive women, sixty-two percent reported having been physically or sexually

81. Cf. Beauchamp & Walters, *supra* note 21, at 32-33.

82. This claim is based on women's being more likely than not to contract AIDS through heterosexual contact. See Ellerbrock et al., *supra* note 50, at 1707.

83. See Rothenberg & Paskey, *supra* note 60, at 1571.

84. See *id.* at 1574.

85. See Richard L. North & Karen H. Rothenberg, *Sounding Board: Partner Notification and the Threat of Domestic Violence Against Women with HIV Infection*, 329 NEW ENG. J. MED. 1194, 1195 (1993). The authors report two cases in which women were shot as a result of having disclosed their HIV status, and other cases of injury to women resulting from disclosure. See *id.*

86. See generally UNDERSTANDING VIOLENCE AGAINST WOMEN 23-48 (Nancy A. Crowell & Ann W. Burgess eds., 1996) (discussing violence against women).

87. See *id.* at 31, 34.

88. See G. Hale-Carlsson et al., *Physical Violence and Injuries in Intimate Relationships—New York, Behavioral Risk Factor Surveillance System 1994*, 45 MORBIDITY & MORTALITY WKLY. REP. 765, 765 (1996) (stating that although the rate of reported violent acts appear similar for women and men, women report more injuries than men).

89. See UNDERSTANDING VIOLENCE AGAINST WOMEN, *supra* note 86, at 7.

90. See Nancy E. Gin et al., *Prevalence of Domestic Violence Among Patients in Three Ambulatory Care Internal Medicine Clinics*, 6 J. GEN. INTERNAL MED. 317, 318-19 (1991); see also Vivian B. Brown et al., *Mandatory Partner Notification of HIV Test Results: Psychological and Social Issues for Women*, 9 AIDS & PUB. POL'Y J. 86, 91-92 (1994) (discussing results of research conducted as part of an intervention trial to reduce drug use and HIV transmission in women); Andrea Carlson Gielen et al., *Interpersonal Conflict and Physical Violence During the Childbearing Year*, 39 SOC. SCI. MED. 781, 784 (1994) (discussing evidence of prenatal and postpartum domestic violence in these socioeconomic groups).

91. See UNDERSTANDING VIOLENCE AGAINST WOMEN, *supra* note 86, at 32.

assaulted, including twenty-seven percent who had been raped.⁹² Assaults of either type (physical or sexual) that were reported to be directly attributable to being HIV-positive were reported by four percent of the sample.⁹³

There are insufficient data with which to make definitive judgments about the benefit/harm ratio of contact tracing for women. On the one hand, contact tracing programs do appear to be effective in reaching women and getting them tested in instances where women may be unaware of their risk exposure.⁹⁴ This benefit is clearly important, given that the rate of HIV infection through heterosexual transmission in women is increasing rapidly.⁹⁵ There appears to be no data on psychosocial or violent consequences for women who are contacted when a male index case discloses her name; this is an area for future research. There is, on the other hand, a growing body of research that suggests that women infected with HIV suffer social harms and seriously are concerned about disclosure of their own status to others.⁹⁶ Given these findings and the extent to which domestic violence against women in general is prevalent suggests the need for building safeguards into any contact tracing program.

IV. RECOMMENDATIONS

First, if a contact tracing program is implemented, it must have a mechanism to screen for a history or risk of domestic violence. There have been significant improvements in domestic violence screening in clinical settings. For example, the Joint Committee on Accreditation of Health Care Organizations (JCAHO) requires screening within hospitals;⁹⁷ the American Medical Association (AMA) encourages physician screening;⁹⁸ and in California, licensed primary care clinics are required to have domestic violence screening protocols.⁹⁹ The extent to which public health programs routinely screen for domestic vio-

92. See Gielen et al., *Women Living with HIV*, *supra* note 69, at 7-8.

93. See *id.* at 9. While this issue has been framed in terms of the HIV-positive woman being the index case, similar concerns could arise when a man learns that he is HIV-positive and blames his own infection on his female partner. There are no data available, however, to determine how often this scenario occurs and what its consequences are.

94. See Rutherford et al., *supra* note 28, at 108 (demonstrating that a large number of women partners of HIV-positive index patients were tested).

95. See Ellerbrock et al., *supra* note 50, at 1704.

96. See, e.g., Pizzi, *supra* note 61, at 1022 (noting that HIV-positive women may avoid disclosing their status for four reasons: (a) concurrence with the societal perception that AIDS, is an illness of gay men and IV drug users, does not really affect women; (b) fear of losing custody of their children; (c) distrust of health care services; and (d) the failure of health care providers to reach out to women); see also North & Rothenberg, *supra* note 85, at 1195 (describing incidents of domestic violence toward and abandonment of HIV-positive women); Rothenberg & Paskey, *supra* note 60, at 1571 (reporting data from a North Carolina study of partner notification that illustrated lack of cooperation by HIV-infected in alerting their sexual partners to their condition).

97. See Anna E. Waller et al., *Development and Validation of an Emergency Department Screening and Referral Protocol for Victims of Domestic Violence*, 27 ANNALS EMERGENCY MED. 754, 755 (1996).

98. See Robert E. McAfee, *Physicians and Domestic Violence: Can We Make a Difference?*, 273 JAMA 1790, 1790 (1995) (discussing the AMA's emphasis on diagnosis and prevention of family violence as an important public health priority).

99. See Ariella Hyman et al., *Laws Mandating Reporting of Domestic Violence: Do They Promote Patient Well-Being?*, 273 JAMA 1781, 1781 (1995) (discussing the need for increased awareness of domestic violence by clinicians and policy makers).

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lence, however, is not known. If a contact tracing program were to be implemented, public health officers must be trained to seek names of contacts when first speaking with index patients, to conduct domestic violence screening with both women and men, and to not inform contacts in cases where there is significant risk. As in other screening programs,¹⁰⁰ referral and support services then need to be available for individuals identified as being at risk for domestic violence. As Karen Rothenberg and Stephen Paskey have suggested, index patients should be allowed to consent to the notification of their contacts due to the risk of domestic violence.¹⁰¹

Second, public resources must be channeled into programs that target primary prevention of HIV infection in men. Given women's primary risk factors,¹⁰² preventing men from becoming infected will, in turn, be important in preventing women from becoming infected. This is not to say that resources should be taken away from programs targeted to women, but that attention should focus on why women are at increasing risk of HIV infection.¹⁰³

Finally, more research must be conducted in many areas to better inform these debates. Before the gender implications of contact tracing programs can be properly evaluated, more research is necessary to suggest whether contact tracing programs are effective in reducing the number of incident cases of HIV and, if so, in which types of settings and for which populations. Research is needed to determine the extent to which HIV-infected men and women already disclose their infection to their partners and the extent to which they understand that their contacts might learn their identities through a public health notification program. Further research is needed to determine whether certain subpopulations disproportionately are burdened or helped as a result of contact tracing programs, including whether this is the result of unjust implementation. And, finally, research is needed to examine the extent to which HIV plays a factor in the already too high rates of domestic violence in this country.

V. CONCLUSION

Scarce information makes it difficult to evaluate the effectiveness of contact tracing programs. Specifically, it is not possible to determine whether contact tracing programs are implemented fairly (fulfilling the principle of justice), nor the extent to which programs accomplish public health goals (beneficence) or violate individuals' privacy or other interests (respect for autonomy). Existing studies indicate that contact tracing programs are more likely to be effective in settings where most contacts do not know they were exposed to HIV and in settings where index patients do not have many anonymous or transient partners. The limited research conducted in this area does not make clear the implications for women. It is reasonable to believe that women who are HIV-negative and have had a partner who is HIV-positive would benefit from contact tracing pro-

100. See Waller et al., *supra* note 97, at 754 (describing efforts to develop an emergency department protocol for the identification, documentation, and referral of victims of domestic violence).

101. See Rothenberg & Paskey, *supra* note 60, at 1573.

102. See *supra* notes 50-51 and accompanying text.

103. See Krystn Wagner & Judith Cohen, *Programs and Policies for Prevention*, in *UNTIL THE CURE: CARING FOR WOMEN WITH HIV* 228, 229 (Ann Kurth ed., 1993).

grams, while potentially some women who test positive for HIV will be harmed, or, at the very least, will fear harm, from the prospect of having their HIV status revealed to others.

The steps that should be taken for the future in this area of public health policy are, first, to determine whether contact tracing programs generally provide more benefit (preventing new cases of HIV) than harm (compromising individual interests) based on beneficence obligations. Second, to the extent to which contact tracing programs are believed to be beneficial, they must be implemented only in conjunction with mandatory screening policies for domestic violence. Similarly, out of respect for autonomy, index patients—male and female—must be counseled on the risks and benefits of having health officials locate their contacts, and must be assured that they need not provide names of their contacts if they believe that doing so would put them at risk of either emotional or physical harm.

The decision whether to implement a contact tracing program, like other public health policies, needs to be based on broader considerations than those addressed in this Article, such as whether the proposed program is the best approach, given limited resources, to achieve the intended goal. Should further research determine that, in some communities, contact tracing is a better use of limited public dollars than other HIV prevention measures, such programs should only be implemented if they are sensitive to the needs of women who potentially could be harmed by such programs.