

# Minority Women and Advocacy for Women's Health

Shiriki K. Kumanyika, PhD, MPH, Christiaan B. Morssink, MA, MPH, and Marion Nestle, PhD, MPH

US minority health issues involve racial/ethnic disparities that affect both women and men. However, women's health advocacy in the United States does not consistently address problems specific to minority women.

The underlying evolution and political strength of the women's health and minority health movements differ profoundly. Women of color comprise only one quarter of women's health movement constituents and are, on average, socioeconomically disadvantaged. Potential alliances may be inhibited by vestiges of historical racial and social divisions that detract from feelings of commonality and mutual support.

Nevertheless, insufficient attention to minority women's issues undermines the legitimacy of the women's health movement and may prevent important advances that can be achieved only when diversity is fully considered.

## WOMEN'S HEALTH ADVOCACY

in the United States does not consistently address problems specific to women in ethnic and socioeconomic subgroups. Numerous differences in the health concerns of minority and majority women have been documented.<sup>1-6</sup> As shown in Table 1, Black women have a shorter life expectancy than White women by 5 years, 50% higher all-cause mortality rates, and death rates from major causes such as heart disease, cerebrovascular diseases, and diabetes that are often 2 to 3 times higher than those for White women. Breast cancer incidence is similar for Black and White women, but Black women have higher breast cancer mortality. Among younger and reproductive-aged women, maternal mortality and homicide rates are 4 times higher for Black women than for White women, and the rate of HIV-related deaths is 12 times higher for Black women. The complexity of women's health advocacy emanates, in part, from the fact that the inequities at issue do not carry over into mortality disparities vis-à-vis men. This is generally true across ethnic groups (Table 1). In contrast, minority health advocacy has been organized primarily around attempts to leverage the data that show striking ethnic disparities in mortality. Thus, taking a minority perspective on women's health may "confuse the issue" to the extent that it draws attention to the favored health status of White women relative to Black women or other women of color.

At issue, then, is how to increase awareness of the special health concerns of minority women within the women's health movement and to ensure that the concerns of minority women are incorporated as integral components of the larger women's health agenda. Although some authorities now argue that the minority health perspective must be included in any discussion of the health of women in the United States,<sup>4-6</sup> the dilemmas that minority women confront in embracing "women's" health may not be generally recognized.<sup>7,8</sup> In this commentary, we describe these dilemmas. Our objective is to help advocates for both minority health and women's health to serve their constituents.

## EMANCIPATION AS AN UNDERLYING THEME

There are profound differences in the outlook and relative political strength of the women's health and minority health movements, but, as with many social movements,<sup>9</sup> both center around a theme of emancipation. With respect to gender, emancipation issues center around the effect of discrimination against women in patriarchal societies, regardless of class, caste, or other such considerations<sup>10</sup>—namely, "glass ceilings," voting rights, and pay equity in comparison with males, as well as reproductive rights, research equity, and access to and equity in health care.<sup>11</sup> These gender issues are a rallying point for social or politi-

cal action among minority women, but minority women also have issues related to race or ethnicity.<sup>12</sup> White women have the luxury of being able to ignore racial biases<sup>13</sup> and are free to focus exclusively (or almost so) on gender problems. In contrast, minority women experience and must simultaneously guard against both racism and sexism.<sup>14</sup> These 2 forces, although similar in some respects, operate independently.<sup>8,15,16</sup>

White women have the advantage of understanding the dominant culture as well as sharing the obligations associated with participation in it.<sup>13</sup> In this sense, the discussion of gender equity among White men and women is a negotiation among *cultural* equals—people who share a common language, norms, and values.<sup>16</sup> Minority women—who have been distanced from the majority culture by history, language, religion, and other factors related to race and ethnicity—do not have the same stake in the majority culture<sup>12,17,18</sup>; they enter discussions of equity with an entirely different set of premises. For example, many minority women may perceive White women as having exploited the civil rights movement to achieve their own goals.<sup>14,19</sup> In addition, middle-class minority women may experience pressure to become assimilated into the dominant culture while also continuing to face reminders of their exclusion from it,<sup>20,21</sup> which hinders their sense of commonality with White women.

**TABLE 1—Gender and Ethnic Comparisons of Selected Health Indicators for US Blacks and Whites**

| Indicator   | Females |       |  | Males |       |  | Gender Difference or Ratio <sup>a,b</sup> |                              |
|---|---------|-------|--|-------|-------|--|---|------------------------------|
|   | White   | Black | Black-White Difference or Ratio <sup>c,d</sup> | White | Black | Black-White Difference or Ratio <sup>c,d</sup> | White Males vs White Females              | Black Males vs Black Females |
| Life expectancy at birth, 1998 <sup>e</sup>   | 80.0    | 74.8  | -5.2   | 74.5  | 67.6  | -6.9   | -5.5                                      | -7.2                         |
| Life expectancy at 65 y, 1998 <sup>e</sup>  | 19.3    | 17.4  | -1.9   | 16.1  | 14.3  | -1.8   | -3.2                                      | -3.1                         |
| Years of potential life lost before 75 y, 1998, age adjusted, all causes, per 100 000 population <sup>e</sup> | 4751    | 9283  | 2.0  | 8352  | 16626 | 2.0  | 1.8                                       | 1.8                          |
| All-cause mortality (per 100 000), age adjusted, all ages, 1996–1998 <sup>e</sup>                             | 358     | 549   | 1.5  | 576   | 921   | 1.6  | 1.6                                       | 1.7                          |
| Cause-specific mortality (per 100 000) within age group, 1997 <sup>f</sup>                                    |         |       |  |       |       |  |   |                              |
| Homicide, 15–24 y <sup>f</sup>  | 3.2     | 13.3  | 4.2  | 13.2  | 113.3 | 8.6  | 4.2                                       | 8.5                          |
| Suicide, 15–24 y <sup>f</sup>   | 3.7     | 2.4   | 0.6  | 19.5  | 16.0  | 0.8  | 5.3                                       | 6.7                          |
| Motor vehicle accidents, 15–24 y <sup>f</sup>   | 18.4    | 11.3  | 0.6  | 39.8  | 32.7  | 0.8  | 2.2                                       | 2.9                          |
| HIV related, 25–44 y <sup>f</sup>   | 2.4     | 29.3  | 12.2   | 13.2  | 76.7  | 5.8  | 5.5                                       | 2.6                          |
| Diseases of the heart, 45–64 y <sup>f</sup>   | 92.2    | 224.6 | 2.4  | 249.0 | 455.5 | 1.8  | 2.7                                       | 2.0                          |
| Malignant neoplasms, 45–64 y <sup>f</sup>   | 213.3   | 276.6 | 1.3  | 247.0 | 416.8 | 1.7  | 1.2                                       | 1.5                          |
| Breast neoplasms, all ages, age adjusted <sup>g</sup>   | 19.0    | 26.2  | 1.4  | ...   | ...   | ...  | ...                                       | ...                          |
| Breast neoplasms, 35–44 y <sup>g</sup>  | 12.6    | 23.6  | 1.9  | ...   | ...   | ...  | ...                                       | ...                          |
| Cerebrovascular disease, 45–64 y <sup>f</sup>   | 19.7    | 56.3  | 2.9  | 25.4  | 87.9  | 3.5  | 1.3                                       | 1.6                          |
| Diabetes, 45–64 y <sup>f</sup>  | 17.2    | 52.9  | 3.1  | 21.3  | 57.3  | 2.7  | 1.2                                       | 1.1                          |
| Maternal mortality (deaths per 100 000 live births), all ages, age adjusted, 1998 <sup>e</sup>                | 4.2     | 16.1  | 3.8  | ...   | ...   | ...  | ...                                       | ...                          |
| Hypertension (%), 20–74 y, age adjusted, 1988–1994 <sup>e</sup>   | 19.3    | 33.8  | 1.8  | 24.3  | 34.9  | 1.4  | 1.3                                       | 1.0                          |
| Osteoporosis (%), females ≥50 y, 1988–1991 <sup>h</sup>   | 21.0    | 10.0  | 0.5  | ...   | ...   | ...  | ...                                       | ...                          |
| Low-birthweight infants (% of live births), 1998 <sup>e</sup>   | 6.5     | 13.1  | 2.0  | ...   | ...   | ...  | ...                                       | ...                          |
| Cancer incidence (new cases/100 000 population), all ages, age adjusted, 1996 <sup>e</sup>                    |         |       |  |       |       |  |   |                              |
| Lung and bronchus   | 43.7    | 47.2  | 1.1  | 68.4  | 101.4 | 1.5  | 1.6                                       | 2.1                          |
| Breast  | 113.3   | 100.3 | 0.9  | ...   | ...   | ...  | ...                                       | ...                          |
| Colon and rectum  | 35.5    | 41.8  | 1.2  | 50.7  | 50.9  | 1.0  | 1.4                                       | 1.2                          |

<sup>a</sup>Life expectancy from birth or 65 y is difference in years for males minus years for females.

<sup>b</sup>Indicators other than life expectancy are ratios (males divided by females).

<sup>c</sup>Life expectancy from birth or 65 y is difference in years for Blacks minus years for Whites.

<sup>d</sup>Indicators other than life expectancy are ratios (Black divided by White).

<sup>e</sup>Data are from the National Center for Health Statistics.<sup>1</sup>

<sup>f</sup>Data are from Hoyert et al.<sup>3</sup>

<sup>g</sup>Data are from the Third Nutrition Monitoring Report.<sup>2</sup>

**DIFFERING EVOLUTION OF HEALTH ADVOCACY**

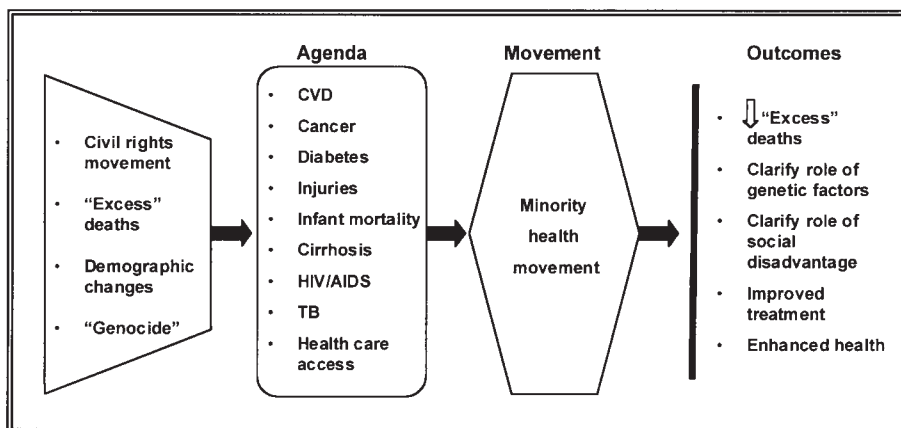
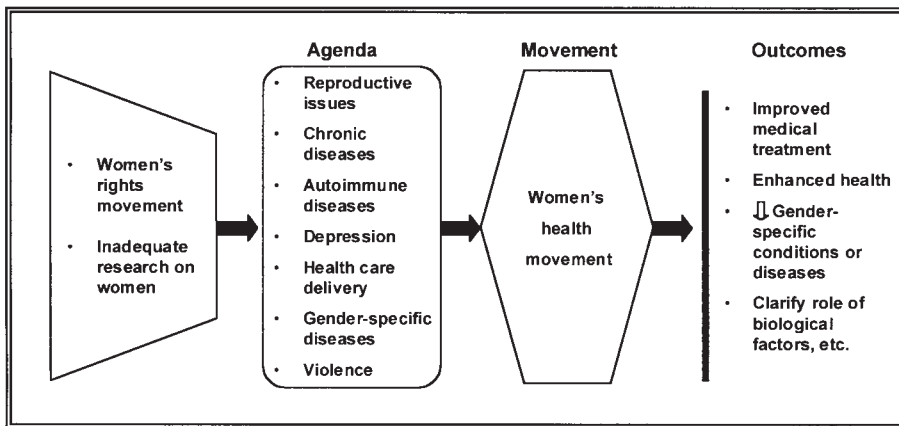
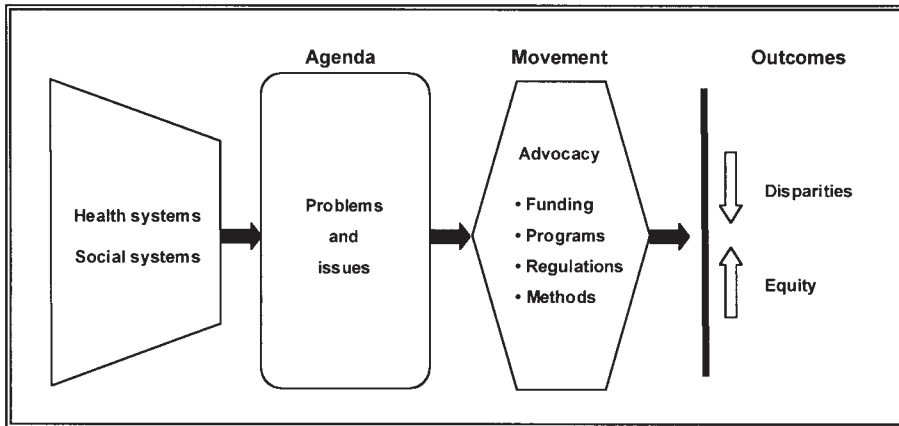
The evolution of the women’s health and minority health movements is depicted schematically in Figure 1 as variations on a general advocacy model. Inequalities or other flaws in health and social systems create specific problems and issues that become

focal targets of social movements<sup>22</sup> and that generate advocacy for special funding, special programs, new regulations, or new methods for accomplishing goals. Successful health movements decrease disparities in health status or health services and increase equality of attention to health concerns. However, there are fundamental differences in the character

of the women’s health and minority health movements.

As shown in Figure 1, the women’s health movement evolved as an offshoot of the modern women’s rights movement that encompassed the activism in the 1960s, the development of the National Organization for Women, the consciousness-raising groups of the 1970s, and the introduction of academic

departments of women’s studies into universities. An important milestone was the *Roe v Wade* decision of 1973, with ensuing legislative struggles over reproductive rights. Such concerns led to increased advocacy for control of more general health matters and to greater attention to women’s issues in mainstream medical research.<sup>7,19</sup> Today, the women’s health agenda includes



Note. CVD = cardiovascular and cerebrovascular disease; TB = tuberculosis.

**FIGURE 1—Schematic portrayal of the evolution of health advocacy in general (top), in women's health (middle), and in minority health (bottom).**

conditions that occur throughout the entire life cycle and all types of diseases, as well as more general problems such as depression, lack of health care, and domestic violence.<sup>4,6</sup> Efforts are made to link this US agenda to global women's health issues.<sup>23</sup> The desired outcomes of successful advocacy for women's health include improvements in medical treatment and decreases in the incidence and prevalence of disease conditions specific to women. An additional goal is to clarify the role of social factors<sup>24</sup> as determinants of women's health and to avoid the reductionist view that health differences between men and women are entirely biological in origin.<sup>25</sup>

In contrast, the minority health movement evolved as an offshoot of the civil rights struggle that is unique to the sociopolitical history of the United States, and it is equally relevant to both sexes. Current advocacy for minority health is anchored in a 1985 federal task force report documenting "excess deaths" among minority groups compared with the White population.<sup>26</sup> For example, the task force found that among Native Americans and African Americans younger than 45 years, death rates were 47% and 42% higher, respectively, than would be expected on the basis of death rates for Whites. For persons 70 years and younger in these 2 groups, 22% and 42% of deaths, respectively, were "excess deaths." Disparities in some areas were seen to have persisted or worsened even in the presence of societal changes intended to improve the condition of minority groups.

The minority health movement is linked to the history of adversarial relations between the White American majority

and people of color. Without regard to gender, these adversarial relations include stigmatization of people with dark skin,<sup>12</sup> legal and de facto segregation and discrimination, and a host of painful historical associations with slavery, the Tuskegee study, involuntary sterilization, and internment in wartime relocation camps.<sup>27–29</sup> At the extreme, the historic events and patterns of discrimination have led some minority observers to charge that the present situation in health care resembles earlier efforts to achieve the genocide—systematic annihilation—of the African American population; they argue that the poor health care in minority communities is a deliberate effort to encourage the gradual disappearance of an unwanted group.<sup>7,29</sup> This deep, historically based distrust of the medical establishment and the mainstream society affects both women and men in minority populations.

Recent scientific and policy shifts may further marginalize minority group members from mainstream health advocacy. For example, the genomic revolution has created a climate that appears to favor biological explanations over social explanations for diseases.<sup>30</sup> Although minority group categorizations are not biological designations,<sup>31</sup> research on ethnic differences has a high potential for being misunderstood in such a climate<sup>32</sup> and could well stimulate a new “eugenics” debate in which racial and ethnic health disparities are attributed to biological inferiority rather than to environmentally determined conditions such as poverty. The fear of such a scenario would tend to create closer allegiances within minority groups across gender lines but

provoke tension within gender groups across ethnicity lines.

### WHITE VS MINORITY WOMEN: THE NUMBERS GAME

Minority women are no less in the minority—numerically, regarding political power, and with respect to the risk of being stereotyped or misunderstood—when the topic is limited to females. The women’s health movement draws on *half* the US population for its constituency, but minorities—men and women—make up only about *one fourth* of the US population. The “minority population,” however, comprises several subpopulations whose only common characteristic is being “non-White,”<sup>31</sup> and women in a specific minority population may constitute as few as 1% (American Indian) or no more than 10% to 12% (Hispanic or African American) of the female population. In contrast, *half* the constituents of the minority health movement or any subset of it would be expected to be women.

Thus, in terms of numbers of constituents and relationship to the White majority, the women’s health movement is more powerful than the minority health movement, even when the diverse minority populations speak as one voice. For numerical reasons alone, minority women might view the women’s health movement as dominated by White women and feel “more equal” when pursuing health advocacy from a minority health perspective. Nonminority women who fail to understand these proportionalities may view minority women who give priority to minority issues (and advocate for both minority men’s and

women’s health) as insufficiently informed about or loyal to women’s rights issues.<sup>7</sup> In addition, in the constant competition for funding and access to the national political agenda, attention to women’s health issues may appear to dilute the resources that might be available for minority issues. This scenario would be less adversarial if the health issues for all women were the same, but, as we explain, they differ in several important respects.<sup>4,6</sup>

### ADDRESSING MINORITY WOMEN’S HEALTH

Considerations of minority women’s health are fraught with vestiges of the historical relations noted earlier, but also with additional issues related to social class. For both minority and majority women, feelings of mutual support may be inhibited by recollections of domestic servitude that reinforce the higher social class basis of the women’s health movement as opposed to the minority women’s health movement. In addition, stereotypical views about Black women and sexuality<sup>29</sup> may inhibit open discussion of reproductive health issues in interracial advocacy forums. Underlying views of abortion diverge between Black and White women; for example, White women generally perceive abortion as an issue of the right of control over their bodies, whereas many African American women view abortion through the prism of “this country’s shameful history of sterilization abuse.”<sup>7</sup>

Within women’s health, views of minority women’s health issues may also be distorted by spurious theories about race-based disease “immunity” and re-

lated biases in medical thinking.<sup>29</sup> Clinicians or researchers may deny or understate the potential relevance to minorities of conditions such as coronary heart disease that at one time had lower prevalences among minorities than among Whites. Although myths and misperceptions may be refuted by hard data—for example, those showing disease rates in minority populations that surpass those in the White population<sup>33</sup>—the availability of data does not immediately erase biases from clinical practice and teaching. Even when discussions are relatively free of stereotypes, biases, and competition between causes, health issues for minority women do not always fit well into the generalities applied to women’s health overall.

### TOWARD A UNIFIED PERSPECTIVE

On February 21, 1998, President Clinton announced an initiative committing the nation to the goal of eliminating by 2010 longstanding disparities in health status that affect racial and ethnic minority groups.<sup>34,35</sup> In light of this initiative, the dilemmas for minority women become even more profound. For women of color, working toward common goals for the benefit of all women, majority as well as minority, requires a suspension of attention to overriding issues of racial bias. This suspension, however, carries a price; it may separate minority women from the support systems that minority communities offer to men and women alike. A focus on gender issues *independent of race*, therefore, requires minority women to choose between racial issues and women’s issues and therefore po-

larizes the debate. For reasons of community support alone, most, if not all, minority women must give priority to struggles against racial and ethnic discrimination. Thus, minority women tend to view women's issues from a perspective that is not shared with any other group—White women, White men, or minority men. This isolation may act as a barrier to social action, professional accomplishment, or health behaviors considered appropriate and desirable by majority women.

Can common ground be found on which to forge alliances to integrate gender- and ethnicity-based health advocacy? Could, for example, the women's health movement (re)frame HIV/AIDS, with its potential for vertical transmission to offspring and its higher burden in Black and Hispanic women,<sup>5,6</sup> as a mainstream women's health issue, even though it might draw resources from health issues more salient for White women? Is it acceptable for policymakers to claim as a breakthrough in women's health a pathway first elucidated in minority women? For example, systemic lupus erythematosus affects more women than men, but it affects more Black than White women and has a poorer outcome in Black women.<sup>36,37</sup> Should studies of Black women with lupus take priority in this field? In contrast, osteoporosis affects proportionately more White than minority women, although all women are at higher risk than men. A consideration of both lupus and osteoporosis as agenda items for the women's health movement could easily be embraced by a broad coalition of women, but the battle for priorities is likely to prove uneven if resources are limited.

A key question for researchers is how the women's health movement can exploit, in a positive way, the element of diversity as a means to better understand disease causation and progression.<sup>38</sup> That is, ethnic differences in disease occurrence or prognosis may be caused by risk factors with different distributions and different time trends by ethnicity—for example, socioeconomic status variables, reproductive patterns, dietary and physical activity practices, alcohol consumption, occupational exposures to carcinogens, area of residence and migration, and certain gene frequencies. The identification of variables that mediate ethnic differences in disease patterns may lead to new etiologic hypotheses for closer study. Lin and Kelsey<sup>38</sup> give examples of how the study of variation within and across diverse ethnic groups has been applied to the study of breast cancer, osteoporotic fractures, and several other health outcomes and discuss the methodological challenges inherent in this approach.

Minority health and women's health constitute different movements and different venues for action. However, many minority women's issues are also, in some form, issues for women in general. Thus, the goals of action for women's health can be mutually supportive even when the perspectives and strategies of participants vary by race and ethnicity. Health aspects on which minority women diverge from White women should not prevent the development of a shared women's health agenda. Recognition and acceptance of differing agendas among women will go much further in facilitating cooperation than will forcing alliances in

which gender is the only permissible variable. ■

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### Contributors

S.K. Kumanyika authored an original draft of this commentary. C.B. Morssink revised the initial article, expanding several themes. M. Nestle added arguments based on her reading of the issues. All authors participated in revisions leading to the final version.

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## Informational Privacy and the Public's Health: The Model State Public Health Privacy Act

Protecting public health requires the acquisition, use, and storage of extensive health-related information about individuals. The electronic accumulation and exchange of personal data promises significant public health benefits but also threatens individual privacy; breaches of privacy can lead to individual discrimination in employment, insurance, and government programs. Individuals concerned about privacy invasions may avoid clinical or public health tests, treatments, or research.

Although individual privacy protections are critical, comprehensive federal privacy protections do not adequately protect public health data, and existing state privacy laws are inconsistent and fragmented. The Model State Public Health Privacy Act provides strong privacy safeguards for public health data while preserving the ability of state and local public health departments to act for the common good.

**ASSESSING POPULATIONAL** health is a core function of state and local public health departments that requires the acquisition, use, and storage of health-related information about individuals.<sup>1,2</sup> National, regional, and statewide governmental public health systems collect vast amounts of public health data regarding communicable (e.g., sexually transmitted dis-

eases [STDs], HIV, tuberculosis), genetic (e.g., newborn metabolic conditions, birth defects), behavioral (e.g., use of drugs, alcohol, and tobacco), and environmental (e.g., pediatric blood lead levels) diseases, conditions, and risks to reduce morbidity and excess mortality.<sup>3</sup>

The accumulation and exchange of these personal data within an increasingly automated

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public health information infrastructure promises significant public health benefits. Well-planned surveillance helps to identify health problems, target interventions, and influence funding decisions.<sup>4</sup> Health information databases facilitate existing and future epidemiologic investigations and research studies. These essential public health functions rely on the quality and reliability of identifiable health information (i.e., any health-related information that reveals, or could reveal under certain circumstances, the identity of the individual who is the subject of the information).<sup>5</sup>

As increasing amounts of identifiable health data are gathered, stored, and exchanged,<sup>6</sup> personal privacy is threatened. Many Americans distrust government agencies<sup>7</sup> and believe that the

collection of personal data without their explicit permission is morally wrong.<sup>8</sup> If public health authorities disclose intimate information, individuals may suffer embarrassment, stigma, and discrimination in employment, insurance, and government programs.<sup>3,9</sup> Persons who fear invasions of privacy may avoid clinical tests and treatments, withdraw from research, or provide inaccurate or incomplete health information.<sup>10</sup>

Congress has unsuccessfully pursued comprehensive health information privacy legislation,<sup>11</sup> but the Department of Health and Human Services recently issued final regulations pursuant to the Health Insurance Portability and Accountability Act of 1996.<sup>12</sup> However, these federal initiatives do not regulate government collection of state public health in-

formation. Since public health is quintessentially a state function, federal privacy rules defer to state public health law under principles of federalism.

Although state public health agencies have an excellent track record of safeguarding public health data, extant state laws concerning public health information privacy are inconsistent, fragmented, and inadequate.<sup>2</sup> These laws differ significantly in the degree of privacy protection afforded, give varying rights to access identifiable data, and allow multiple exceptions to disclosure prohibitions outside public health agencies.<sup>2</sup> Some states' laws declare that public health records are private, but they are silent about the degree of protection of privacy. Laws often fail to narrowly define who may have access to such data and to require persons to demonstrate why they need access. Statutes often lack specificity about when disclosures may be made, permissively allow disclosures to persons or for purposes that are inconsistent with those of public health (e.g., disclosure in legal settings through court orders or subpoenas), or fail to address secondary disclosures of information beyond those used to justify the original collection. In some states, disclosure provisions are too strict, interfering with legitimate public health exchanges of identifiable data among in-state and out-of-state public health agencies.

Current law and policy often fail to reconcile individual privacy interests with collective public health interests in identifiable health data. Civil libertarians and consumers see informational privacy as a fundamental right and stress the importance of stronger legal safeguards. Pub-

lic health professionals, on the other hand, strongly assert the need to use data to achieve important public health purposes. To reconcile these 2 divergent approaches, the Georgetown/Johns Hopkins Program on Law and Public Health convened a multidisciplinary team of privacy, public health, and legislative experts to propose a model public health information privacy statute.<sup>13</sup> The Model Act would provide, for the first time, strong and consistent privacy safeguards for public health data, while still preserving the ability of state and local health departments to act for the common good. The Centers for Disease Control and Prevention recommends that states consider adopting the model legislation to "strengthen the current level of protection of public health data."<sup>14</sup> In this commentary, we explain the Model Act and the principles that underlie its protections.

### RECONCILING PUBLIC HEALTH AND PRIVACY INTERESTS

Some scholars perceive a conflict between individual privacy interests (which seek strict limits on data uses) and public health interests (which seek more expansive data uses for the common good).<sup>15,16</sup> This conflict, while complex and difficult, often can be resolved. The Model Act's approach is to maximize privacy safeguards where they matter most to individuals and facilitate data uses where they are necessary to promote the public's health. This accommodation between privacy and public health balances individual and collective interests.

Consider the sequence of events when a government

agency collects public health data through, for example, reporting or other forms of surveillance. First, the agency *acquires* the data, typically after the patient has given informed consent (usually to a medical care provider) to provide a biologic sample (e.g., blood or urine) or health-related behavioral information (e.g., sexual history or drug use practices). Given that there is a strong public health interest, most people believe that patients should accept this invasion of privacy for the collective good. Next, the agency *uses* the data strictly within the confines of the health department. Again, if the agency has a strong public health interest and the data are shared only with agency officials who have a need to know, data uses should prevail over privacy. When public health authorities acquire and use data strictly within the agency, public health benefits are at their highest and risks to privacy are at their lowest. The agency needs the freedom to use the data to monitor and prevent health risks. If public health authorities do not disclose the identifiable data outside the agency, patients face few social risks.

Finally, the agency may be asked or, under unusual circumstances, may seek to *disclose* personally identifiable information to persons outside the agency—for example, to employers, insurers, commercial marketers, family, or friends. These kinds of disclosures are not very important for the public's health, but they do place patients at considerable risk of embarrassment, stigma, and discrimination. For these reasons, the law ought to provide maximum protection of privacy. The Model Act's approach, therefore, is to give gov-

ernment flexibility to acquire and use data strictly within the mission of the public health agency, providing it can demonstrate an important public health purpose. However, the Model Act affords public health authorities very little discretion to release personally identifiable data outside the agency and imposes serious penalties for disclosures without the patient's informed consent.

### THE MODEL STATE PUBLIC HEALTH PRIVACY ACT

The Model Act is structured to protect privacy and security interests without thwarting public health goals underlying the acquisition, use, disclosure, and storage of identifiable health data at the state and local levels. Figure 1 provides a flowchart image of the Model Act, the design of which is based on several core assumptions.

*Public health and privacy are synergistic.* The debate surrounding public uses of identifiable data and individual privacy assumes that these interests are mutually exclusive. This is not invariably the case, however. Public health agencies have significant interests in protecting the privacy of health-related information. Protecting individual privacy encourages individuals to voluntarily participate in public health and individual health care programs and to freely divulge personal information, thus improving the reliability and quality of data.<sup>4</sup> Privacy advocates (and others) benefit from a well-functioning, efficient public health system that works to improve population health outcomes. In these ways, public health and privacy are synergistic, thus suggesting that the Model Act, if passed, would actually im-

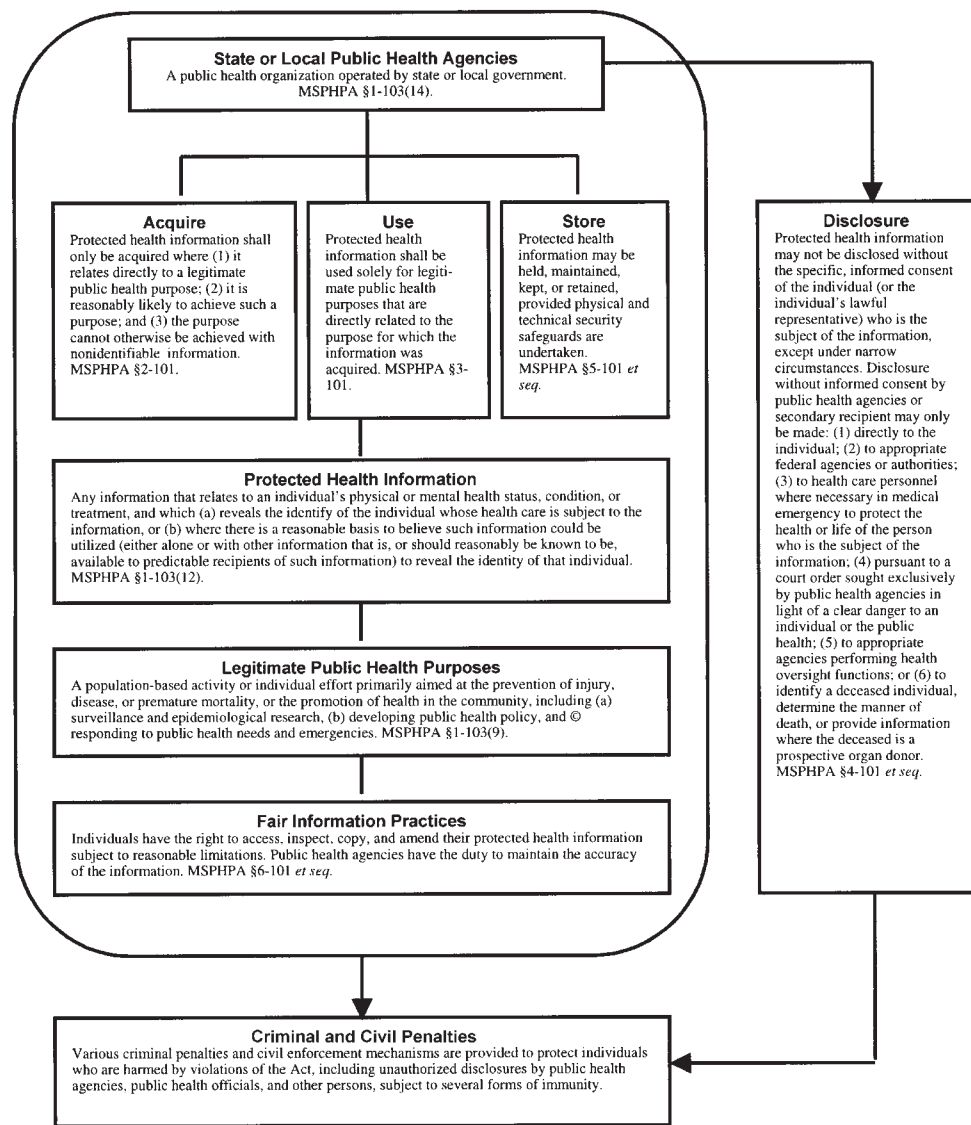


FIGURE 1—The Model State Public Health Privacy Act.

norities) in the protection of some nonidentifiable information, the Model Act only regulates in favor of individual privacy interests. Protected health information includes only health information (1) that reveals the identity of the individual whose health care is the subject of the information (e.g., health data that refer to the name, social security number, or any other information about the person who is the subject of the data) or (2) that, in cases where there is a reasonable basis to believe, could be used (either alone or with other information that is known to be available to predictable recipients of such information) to reveal the identity of that individual. Under this latter category of protected health information, even aggregate statistical data may be identifiable. Consider, for example, statistical data that reveal that a Native American female in a small county is infected with HIV. If this information can be used to identify this individual because the ethnic group membership is sufficiently small in the county, the data are individually identifiable under the Model Act. Since nonidentifiable information cannot infringe individual privacy, the act requires public health agencies, whenever possible, to use data stripped of personal identifiers.

*Acquisition and use are contingent upon legitimate public health purposes.* The Model Act regulates the ways in which public health agencies acquire, use, disclose, and store protected health information. It safeguards privacy, in part, by requiring public health authorities to demonstrate a legitimate public health purpose for the acquisition and use of data. The act defines “legitimate public

prove public health outcomes, not thwart them.

*All identifiable health information deserves legal protection.* The Model Act applies to all “protected health information” held by public health agencies. This includes any public health information, whether oral, written, electronic, or visual, that relates to an individual’s past, present,

or future physical or mental health status, condition, treatment, service, product purchases, or provision of care. This broad definition of protected health information recognizes that any identifiable data (e.g., HIV, STD, or immunization status) can be sensitive.

*Nonidentifiable health information requires no protection.* The

definition of “protected health information” specifically incorporates another core assumption: nonidentifiable health data do not merit privacy protection. Where health data are truly nonidentifiable, individual privacy interests are not threatened. Notwithstanding the interests of societal groups (e.g., ethnic, racial, or religious mi-



health purpose” to mean a population-based activity or individual effort primarily aimed at the prevention of injury, disease, or premature mortality, or the promotion of health in the community (see Figure 1). Such efforts include carrying out public health surveillance, conducting epidemiologic research, developing public health policy, and responding to public health needs and emergencies. While interpretation of a legitimate public health purpose may admittedly narrow or broaden the scope of the act, it allows flexibility in prioritizing various state public health activities across jurisdictions.

In addition to imposing a requirement to justify data acquisition, the Model Act limits the use of identifiable information within the agency. In particular, it specifies that (1) nonidentifiable data must be used whenever possible, (2) the sharing of identifiable data among public health officials must be limited to the minimum amount necessary, (3) public health officials may have access to identifiable data only if they have a demonstrable need to know, and (4) agencies must protect security by maintaining the data in a physically and technologically secure environment.

*Disclosures must be strictly limited.* While the Model Act affords public health agencies the power to acquire and use health data for important public health purposes, it grants very little authority to disclose identifiable data outside the public health system. The act clarifies that protected health information is not subject to public review (e.g., inspection, dissemination, or investigation by members of the public) and may not be disclosed without the specific informed consent of the in-

dividual who is the subject of the information (or the individual’s lawful representative), except under narrow circumstances.

Disclosures without informed consent may only be made as follows.

1. Directly to the individual. For example, a public health agency may contact an individual about identifiable health information it has about the individual without that person’s consent.
2. To appropriate federal agencies or authorities. As a model *state* law, the Model Act cannot restrict federal demands for identifiable information under constitutional principles.
3. To health care personnel where necessary in a medical emergency to protect the health or life of the person who is the subject of the information from serious, imminent harm. This exception is exceedingly narrow. It would not allow, for example, a disclosure to protect the health of a person who is not the subject of the information, such as a health care worker who was injured by a needle that may have been used by an individual infected with HIV.

4. Pursuant to a court order sought exclusively by public health agencies in light of a clear danger to an individual or to the public health that can be averted or mitigated only through a disclosure by the agency. This is the only exception for the disclosure of protected health information pursuant to a court order.

5. To appropriate public or private agencies performing health oversight functions relating to the public health agency as authorized by law.

6. To identify a deceased individual, determine the manner of

death, or provide information in cases where the deceased is a prospective organ donor.

Secondary disclosures by recipients of protected health information from public health agencies are specifically prohibited without individual informed consent or authorization under the narrow exceptions. Naturally, this prohibition does not apply to the (a) individual subject of the information, (b) persons authorized to make health care decisions for the individual, or (c) any person who is specifically required by federal or other state law to disclose the information.

Finally, the Model Act permits the exchange of data among public health agencies within and outside the state. These information exchanges are viewed as data *acquisitions* or *uses*, not *disclosures*. As such, public health agencies may exchange identifiable health data with other state or local agencies provided the exchanges are necessary for the public’s health. For example, comparing HIV and tuberculosis registries among state and local health agencies is an important public health function, given the strong relationship between these two diseases.

## FAIR INFORMATION PRACTICES

Safeguarding privacy requires data holders to engage in a range of fair information practices. These practices ensure strong security and privacy of public health information, but they do not unreasonably burden public health authorities. The act incorporates the following fair information practices.

## Justifying the Need for Data Collection

Acquiring identifiable data is not an inherent good. Rather, public health authorities must substantiate the need for identifiable data. As discussed above, the Model Act affirms that public health agencies shall only acquire identifiable health information that (a) relates directly to a legitimate public health purpose and (b) is reasonably likely to achieve such a purpose. When information is no longer needed to fulfill the purpose for which it is acquired, it must be expunged or made nonidentifiable.

## Informing Data Subjects

The act acknowledges that individuals are entitled to know how information about them is being used. Public health agencies may not acquire identifiable data without public knowledge. Before acquiring such data, public health agencies must provide public notice (through written information distributed in such a way as to reasonably inform the public) concerning their intentions to acquire the data and the purposes for which the data will be used. Individuals are entitled to view records of disclosures of their protected health information, which public health agencies are required to maintain.

## Access to One’s Own Data

Subject to reasonable limitations, individuals are entitled to access, inspect, and copy their health data. Public health agencies are required to explain to individuals any code, abbreviation, notation, or other marks appearing in the information, as well as to ensure the accuracy of such data and amend any errors.

## Ensuring Privacy and Security

Public health agencies have a duty to adhere to privacy and security safeguards. Specific protections are administered by a designated health information officer appointed by each public health agency and enforced through significant administrative, criminal, and civil penalties. These protections apply to identifiable health data, regardless of their holder, through various provisions of the act that (a) require an affirmative statement of privacy protections to accompany the disclosure of protected health information and (b) apply similar criminal and civil sanctions for unlawful disclosures to public health officials as well as secondary recipients.

## CONCLUSION

The Model State Public Health Privacy Act is a product of consensus-building among nationally prominent experts in privacy and public health.<sup>12</sup> The National Conference of State Legislatures plans to make the act available to state legislators interested in promoting health information privacy.<sup>17</sup> At least one state legislature, Texas, has introduced a version of the Model Act to date.<sup>18</sup> Proposed legislation concerning health information privacy in New York has incorporated some of the language and principles embodied in the act.<sup>19</sup>

Although not perfect, the act provides a balance between the social good of data collection (recognizing its substantial value to community health) and the individual good of privacy (recognizing the normative value of respect for persons). It authorizes public health agencies to acquire, use, and store identifiable health

data for public health purposes while simultaneously requiring them to respect individual privacy and imposing stiff penalties for failure to comply. Individuals are empowered with various privacy rights and remedies for breaches of these duties. The community generally is sympathetic to data collection for public health purposes, but it seeks strong legal protection against potentially harmful uses of personal information. States that adopt the act or laws consistent with its structure can stabilize and modernize public health information practices. If the act serves as a model across multiple jurisdictions, it could reduce the variability of existing protections among states, allow for the responsible exchange of health data within a national public health information infrastructure, and ultimately improve public health outcomes. ■

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L.O. Gostin convened and chaired the panel (of which J.G. Hodge and R.O. Valdiserri were members) to develop the Model State Public Health Privacy Act. L.O. Gostin and J.G. Hodge drafted the act with the assistance of the panel. All 3 persons contributed to the writing of the commentary.

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