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## Categorizing Variables to Improve Population Health and Equity

# Coupled Ethical—Epistemic Analysis of Public Health Research and Practice: Categorizing Variables to Improve Population Health and Equity

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The categorization of variables can stigmatize populations, which is ethically problematic and threatens the central purpose of public health: to improve population health and reduce health inequities. How social variables (e.g., behavioral risks for HIV) are categorized can reinforce stigma and cause unintended harms to the populations practitioners and researchers strive to serve.

Although debates about the validity or ethical consequences of epidemiological variables are familiar for specific variables (e.g., ethnicity), these issues apply more widely.

We argue that these tensions and debates regarding epidemiological variables should be analyzed simultaneously as ethical and epistemic challenges. We describe a framework derived from the philosophy of science that may be usefully applied to public health, and we illustrate its application. (*Am J Public Health*. 2015;105:e36–e42. doi:10.2105/AJPH.2014.302279)

### HOW EPIDEMIOLOGICAL

variables are categorized may result in real-world effects that reinforce stigma and cause unintended harms to the populations that public health professionals strive to serve. Debates about the validity or ethical consequences of variable choice are relatively familiar in the literature on ethnicity and race, but we suggest these problems apply more widely. We contend that stigmatizing vulnerable populations is ethically problematic, as has been previously established, and it more fundamentally undermines the purpose of public health research and practice: to improve population health and reduce health inequities.<sup>1</sup> We outline some tensions that researchers face when categorizing variables and argue that these issues benefit from being approached as problems that are analyzed simultaneously as ethical challenges and as epistemic or evidentiary challenges. We present a framework, derived from the philosophy of science, as an approach that could be usefully applied to public health. We apply this framework to 2 examples: the use of men who

have sex with men (MSM) as a variable in US blood bank policies and the use of the Scottish Index of Multiple Deprivation (SIMD) in health disparities policy.

### PUBLIC HEALTH GOALS AND THE PROBLEM OF STIGMA

It is widely accepted that a fundamental purpose of public health is ameliorating unacceptable health inequalities or health disparities.<sup>2,3</sup> Some authors highlight the underlying importance of ethics by preferring the term “health inequities,” which is defined as the patterns of health outcomes that may be viewed as unfair or unjust. This seemingly minor distinction—between inequalities and inequities—forms the basis for why it is necessary to reexamine public health variables from a perspective that incorporates ethical analysis into the more obvious epistemic and evidentiary tasks of research.<sup>4</sup> Public health research and practice seek to maximize the health of a population and are concerned with the amelioration of disease patterns that are judged ethically unacceptable. Under this

interpretation, which we endorse, public health is inseparable from its ethical goals.

Although public health professionals seek to ameliorate unjust population health patterns, they simultaneously must remain vigilant to avoid doing further harm by stigmatizing the populations. For example, a 2009 set of recommendations for ethical practices in epidemiology notes,

Research in epidemiology (as well as such other fields as genetics and sociology) may present risks to the interests of communities, societies, or racially or ethnically defined groups. Information might be published that could stigmatize a group or expose its members to discrimination.<sup>5(p39)</sup>

Although it is of course valuable to perform ethical analyses of public health projects, we feel coupling ethical and epistemic perspectives in a more integrated manner is fruitful. In particular, the ethical implications of the way variables are constructed should, in many situations, result in an approach that explicitly considers the interplay between ethics and methodological choices, rather than treating these as separate sets of considerations.



## SOCIAL CONSTRUCTION OF PUBLIC HEALTH VARIABLES

Because a public health perspective considers populations, an appropriate variable for practice and research must be amenable to meaningful measurement across multiple individuals. In other words, for epidemiology and related disciplines to proceed, it is necessary for individuals to be classified into categories that share some common characteristics. Inevitably, heterogeneity will exist within any category in which individuals are grouped together. Nevertheless, some categorizations will contribute to the achievement of public health goals more effectively than will others.<sup>6</sup> The term “social construction” highlights the multiple ways a variable could be conceptualized, with the researchers’ social position and prior experiences influencing their choices.

To say that variables are socially constructed is not to deprecate those variables. Philosophers have long debated scientific realism, the assertion that scientific terms can, and often do, closely reflect real entities in the world.<sup>7,8</sup> The textbook example of the social construction of variables is the long-standing dispute over the scientific, including epidemiological, legitimacy of human races. The (nonunanimous) consensus is that these population variables are far more closely tied to human imagination and social patterns than to humans’ innate biological nature.<sup>9–14</sup> Nevertheless, the problems arising from the use of socially problematic (and socially constructed) variables apply far

more broadly than only to race. The combination of biological phenomena, social construction, and public application calls for an analysis that blends evidentiary and ethical considerations.

## ETHICAL AND EPISTEMIC DIMENSIONS

Both genuine causal variables and proxy variables are used in research and practice, but clear distinctions between the 2 are often not made. Proxy variables have the potential to become so methodologically and culturally pervasive that they can act as routine stand-ins for complex or poorly understood causal forces; their epistemic weaknesses are forgotten and they are taken at face value instead of as representatives of something else. When these proxies have ethically problematic consequences (e.g., stigmatizing residents in a neighborhood that is classified as deprived), the epistemic features feed into the ethical features. When the ethical features are taken into account in the construction of variables (e.g., careful consideration of the appropriate use of neighborhood deprivation variables because of the risk of stigmatization), the ethical features feed into the epistemic features. As a result of the ethical and epistemic dimensions of variable construction feeding into each other, the ethical and epistemic features of the variables become coupled.

The intertwined evidentiary complexities and ethical problems of variables in etiological research are apparent in the example of

male same-sex sexual behavior and HIV risk.<sup>15</sup> When researchers or practitioners are studying HIV transmission patterns, they must make choices about how to define the population of interest and identify exposure variables therein. If the research is monitoring trends in HIV serostatus or AIDS cases, the variables MSM or homosexual men may well be appropriate.<sup>16,17</sup> However, a new complication arises when research aims to uncover the etiology of HIV/AIDS patterns or when a policy seeks to respond to assessments of its etiology. Then, the use of an independent variable such as MSM becomes problematic because it is not sexuality per se that produces the risk; it is certain unprotected sexual behaviors performed between HIV-negative individuals and HIV-positive partners.

Aside from any particular sexual behaviors, an HIV-negative man’s risk of contracting HIV from having sex with a man is further exacerbated by the legacy of elevated rates of HIV in the population of potential partners for MSM. Put in other terms, the epistemic or evidentiary challenge is that the exposure variables are particular sexual activities within certain background infection rates, whereas the MSM behavioral category is a proxy, surrogate, or indicator. However, using homosexual men or MSM as a proxy variable in HIV etiological research or in practice can exacerbate homophobic stigma by portraying male homosexuality as inherently diseased. This ethical problem, in turn, risks generating new epistemic problems by creating distrust between

these populations and professionals attempting to research HIV in the future.

A second example of intertwined ethical and epistemic issues in variable construction is provided by considering the different measures used to study socioeconomic position (with the term “socioeconomic status” often used synonymously). Although several distinct dimensions of socioeconomic position can be discerned (e.g., education, occupation-based social class, or wealth), each of these can be constructed in different ways.<sup>18,19</sup> In the United Kingdom, area-based deprivation, on the basis of combining routinely available administrative and census data, is frequently used.<sup>20–22</sup> Area-based deprivation measures are particularly helpful in guiding resource allocation and may be of some assistance in guiding area-based interventions. However, the use of such measures raises epistemic concerns because area-based deprivation has been frequently used as a measure of individual socioeconomic position. In other words, area-based deprivation measures are often used as a proxy variable for individual-level causal forces.

The implications of these different variable constructions may be overlooked so that area-based policy measures may be preferred, rather than interventions that address inequalities in wealth or income, for example. This choice of variable therefore affects the approach adopted in policy and practice, which in turn raises epistemic issues (e.g., the underascertainment of rural poverty), which subsequently raises ethical



issues (e.g., underfunding programs that ameliorate rural poverty).<sup>23</sup>

## COUPLED ETHICAL- EPISTEMIC ANALYSIS

There is an extensive literature on the evidentiary or epistemic aspects of variables in public health that examines issues such as whether a variable represents a proxy or causal factor.<sup>24–26</sup> Similarly, there is a large body of research on the ethics of population variables in public health that examines issues such as the stigmatization and coercion of high-risk populations.<sup>27,28</sup> Although there are exceptions,<sup>29</sup> there is currently a split between these 2 ethical and epistemic lines of inquiry into variables, yielding 2 disunited but valuable bodies of literature that, when taken together, remain unable to fully capture the range of conceptual and practical complexities.

We suggest a third position: approaching the problem of constructing and applying population variables as a case of what philosopher Nancy Tuana calls “coupled ethical–epistemic issues.”<sup>4</sup> Tuana has developed this approach as a means for linking ethical and evidentiary analysis while integrating them into collaborative science. Her development of the concept draws on the successes and failures of bioethics and other fields and is primarily explored in its application to decision-making processes related to climate change.<sup>30</sup> Climate science, like public health, is a field in which there is a broad consensus that an ethical imperative exists to ameliorate risks faced by the public

but that those risks are bound up in practical and theoretical questions of uncertainty and methodology. Because of these similarities, methods developed in the context of climate change have the potential to provide new insights into public health. Although not all public health problems might require such an approach, the complexities of constructing population variables demonstrate how intertwined evidence and ethics are in public health.

### Men Who Have Sex With Men

In the United States, there is vehement debate over the long-standing Food and Drug Administration (FDA) policy of permanently banning from its potential blood donor pool every man who has had sex with a man since 1977.<sup>31</sup> The basic rationale behind this decision is quite strong: 57% of annual reported HIV cases in the United States are MSM, so excluding such a high-incidence population could be an easy method of reducing HIV-positive blood donors.<sup>32</sup> One key problem is that male–male sexual behaviors vary enormously in riskiness, thus leading to heterogeneous risk profiles for those who fall under the broad MSM category. Not everyone in the MSM category has a high HIV risk.

In light of the high sensitivity of contemporary blood bank testing protocols, recent years have seen an international trend toward adopting temporary (rather than permanent) deferrals following MSM activity,<sup>33</sup> even though the new policies presumably slightly increase the absolute risk of transfusion-transmitted infection.

For example, a retrospective model of blood donation data of 2005 to 2007 estimates that converting the lifetime ban into a 12-month ban in England and Wales, as is the new policy, would result in 1 additional “HIV infectious donation every 455 years.”<sup>34(p85)</sup> The FDA has resisted the trend, despite opposition from the American Red Cross and the American Association of Blood Banks.<sup>31</sup> Survey research on MSM indicates that “a one year MSM deferral (since last having sex with a man) was viewed as a generally acceptable, equitable, and sufficiently cautious alternative.”<sup>35(p4)</sup> Although the FDA policy seeks to prevent harm and “minimizes even the small risk” of transfusion-transmitted infections,<sup>36</sup> it does not take into account the complex interplay between epistemic strategies and ethical judgments. The epistemic and ethical repercussions of the policy extend far beyond inputs into the blood bank system. The FDA Web site’s question and answer section addresses the concern that the policy is discriminatory by explaining that it “is not based on any judgment concerning the donor’s sexual orientation.”<sup>36</sup> Although no homophobic condemnation is intended by the policy, the use of MSM as a proxy variable for causal forces in an implied etiological context (screening) makes homophobic social stigmatization of MSM and internalized homophobia predictable social harms. The variable MSM is further complicated by its inseparability from the FDA’s goal of convincing the public that it is minimizing blood supply risks, which is achievable

through different means (e.g., education campaigns). The current policy is arguably more effective at convincing the public because of negative stereotypes associating HIV risk with gay men.

Epistemically, the etiology of HIV transmission is being crudely characterized. Ethically, stigma against MSM weighs against the policy. Uniquely, a coupled ethical–epistemic approach goes beyond listing the different ethical and epistemic features, because it also highlights interplay between the 2 considerations. The ethical problem of promoting stigma feeds into an epistemic problem because stigma impedes free and open interactions between patients and health care providers, including HIV testing and other prevention efforts, which leads to lower quality data regarding HIV prevalence and related monitoring.<sup>37</sup> Conversely, the epistemic choice of representing HIV risk with the broad proxy variable MSM causes ethical problems by missing a public education opportunity to share information about which sexual behaviors carry the highest risks and in which contexts.

### The Scottish Index of Multiple Deprivation

Scotland experiences large inequities in health, and addressing these is a priority for the Scottish government. In 2008, the Scottish government published its Equally Well policy, which resulted in the establishment of several targets for the reduction of health inequalities.<sup>38</sup> Many of these are monitored using an area-based deprivation measure, the SIMD, which



ranks areas (with a median population of approximately 750 people) from the most to the least deprived.<sup>23</sup> It is also widely used for research purposes in Scotland.

Epistemically, the SIMD has numerous important advantages. Because it is derived from administrative data, the measure can be readily calculated and applied as a proxy measure for individuals in the Scottish population. This can be a particular advantage when analyzing data sets; however, as with any variable, disadvantages exist. Although SIMD is calculated on the basis of small areas, it is often a proxy for the causal factor of interest (unless the causal factor of interest actually operates at an area level, e.g., access to services). This can be illustrated by the finding that a majority of those experiencing individual-level socioeconomic disadvantage (such as low income or unemployment) do not reside in the most deprived SIMD quintile.<sup>39</sup> Similarly, many individuals living in areas of deprivation may actually be relatively socioeconomically advantaged. From an ethical perspective, regularly available statistics facilitate the monitoring of health inequalities and thereby highlight the ongoing need for action. However, SIMD may conceal the needs of individuals outside areas of deprivation, thus neglecting their needs.

As with the MSM variable, a complex interplay exists between the epistemic and ethical features of SIMD. The epistemic dominance of SIMD for research and monitoring health inequalities has important ethical implications. Conceptualizing the causal force at an area level favors an

understanding among policymakers and practitioners that area-based interventions will reach those most in need; however, this may not be the case.<sup>23,40</sup> Following the Equally Well Ministerial Taskforce, much of the policy focus to address health inequalities was through delivery of area-based interventions (especially cardiovascular risk screening). There was arguably less continued emphasis on how people experiencing individual—but not area-level—socioeconomic disadvantage would benefit (which might favor alternative approaches, e.g., population-based measures). Furthermore, residents of areas ranked as multiply deprived have raised concerns because they experience stigma in their day-to-day lives that may be created or reinforced by the use of area-based deprivation measures.<sup>41–43</sup> A potentially adverse epistemic consequence of the focus on area-based measures is that future research may downplay the investigation of individual-level socioeconomic disadvantage and population-based approaches to intervention. These in turn result in important longer-term ethical impacts.

There are clear ethical and epistemic benefits and risks to the use of SIMD as a variable in public health. Abandoning the use of area-based deprivation measures would risk seriously undermining necessary efforts to monitor trends in health inequalities.<sup>44</sup> However, an integrated approach to the consideration of ethical and epistemic features may assist researchers and practitioners to choose SIMD in circumstances in which its use favors public health

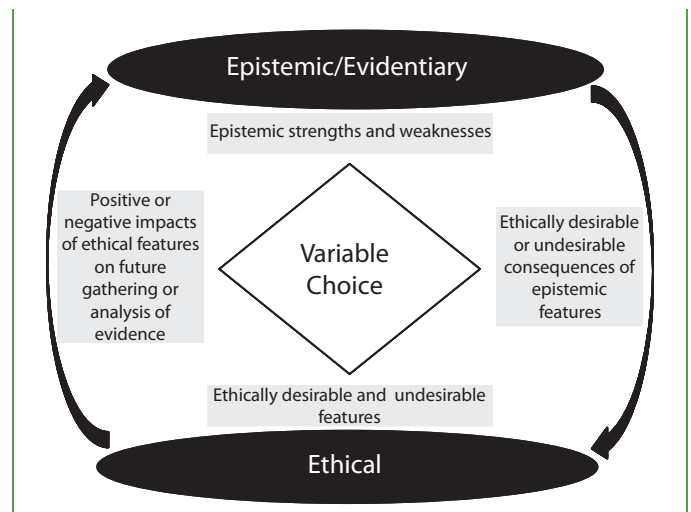
goals and fosters reflective practice to minimize disbenefits.

### THE CONTINUED NEED FOR EXPLICIT THEORIZATION

Theorization about variables must occur in both epistemic and ethical domains. In relation to epistemology, it is crucial that researchers distinguish between the use of variables representing a putative causal factor and the use of a proxy variable. The use of a proxy variable is by no means inappropriate, particularly because of the increasing potential for secondary analysis of data sets and administrative data. However, irrespective of whether primary or secondary data analysis is being conducted, it would appear reasonable for a justification for the choice of a proxy variable to be considered and for some reflection over potential limitations. Issues about validity of variables apply

even when variables are incorporated only as covariates, especially because proxy variables that do not adequately correlate with the causal factor of interest may result in inadequate adjustment of confounders.<sup>45</sup> Furthermore, it would potentially improve the positive impacts of research if the likely implications of the choice and categorization of variables on real-world practice and policy were considered.

The explicit analysis of variables poses several challenges. It requires engagement with those in a diverse array of other disciplines, including ethicists, philosophers of science, and social scientists as well as public stakeholders. It also asks public health professionals to critically reflect on the underlying values of the discipline. We suggest that issues of equity are central to these considerations but acknowledge the normative nature of such a debate and the need for ongoing discussion.



**FIGURE 1—Coupled ethical-epistemic features of public health variables.**





**TABLE 1—The Application of Coupled Ethical–Epistemic Analysis to 2 Public Health Examples**

Public Health Example	Analysis Questions		
	What are the chosen variables' strengths and weaknesses for evidence gathering and analysis?	What are the chosen variables' ethical strengths and weaknesses?	How will the chosen variables' strengths and weaknesses for evidence gathering and analysis affect ethical issues?
The use of MSM as a proxy variable in the FDA policy permanently banning high-risk donors	The current policy uses a proxy variable, MSM, to identify potential blood donors who have an elevated average HIV risk. It is unclear whether alternative variables could be used without sacrificing sensitivity in detecting individuals with HIV. The MSM proxy variable is a stand-in for individual histories of sexual behaviors (the underlying causal variables), which conceals known heterogeneity in risk.	The permanent donation ban is probably marginally more effective than are alternative policies (e.g., 1-year donation deferrals) at preventing transfusion-transmitted infections. The use of the MSM proxy variable instead of known causal variables promotes stigma against the MSM population as being at inherently high risk of disease.	Promoting stigma, even unintentionally, against MSM impedes future testing and other HIV prevention programs. Increases in stigma against MSM may undermine future research on the MSM population by making the enrollment of participants into research projects more difficult.
The use of SIMD as a proxy variable in studying socioeconomic deprivation	SIMD is a carefully constructed variable for measuring area-based deprivation. It is frequently used as a proxy variable for individual-level socioeconomic position. This may be reasonable when the latter is unavailable (which is often the case in many data sets), but careful thought is required about its validity as a proxy. The proxy is often used instead of individual-level measures and therefore often used for area-based targeting of interventions, which may be more appropriately targeted at certain socioeconomic groups.	Area-based measures can help guide the planning of services and the delivery of interventions and facilitate the routine monitoring of health inequities using readily available administrative data. Some areas experience negative public perceptions, often caused or exacerbated by the use of area-based deprivation measures. This may perpetuate a poor quality of environment (e.g., by discouraging new businesses from opening in these areas).	Geographical targeting on the basis of area-based deprivation could result in individuals living within these areas being unwilling to take part in future research if they feel they have been stigmatized by area-based measures. Focusing health-promotion efforts on area-based deprivation shifts research attention away from individual-level socioeconomic disadvantages. Area-based interventions seek to benefit those living in the areas described, but their routine or institutionalized use can make it difficult to alternatively pursue population-based (rather than area-based) programs or policies, even if those alternative approaches would be more effective.

Note. FDA = Food and Drug Administration; MSM = men who have sex with men; SIMD = Scottish Index of Multiple Deprivation.



## AN APPROACH TO COUPLED ETHICAL–EPISTEMIC ANALYSIS

Public health professionals can begin the process of adopting a coupled ethical–epistemic approach by asking themselves a series of questions. Figure 1 provides an aide-mémoire, and Table 1 summarizes 2 examples of their application.

1. What are the chosen variables' strengths and weaknesses for evidence gathering and analysis? The chosen variables' evidentiary strengths and weaknesses often receive the greatest attention, and most researchers will be comfortable in critically scrutinizing the extent to which a chosen variable adequately measures a causal factor. For example, contemporary debates about the effect of obesity on all-cause mortality frequently consider the adequacy of commonly used measures, including body mass index, waist circumference, and waist-to-hip ratio.
2. What are the chosen variables' ethical strengths and weaknesses? By contrast to the detailed debate regarding the epistemic strengths and weaknesses of variables, less attention is paid to the ethical impacts of how variable choice affects social understandings of the populations being categorized. The choice of variables may result in social stigma being implicitly reinforced and therefore is ethically undesirable. By contrast, some variables may uncover

a previously undetected (or neglected) health problem in a marginalized population and therefore are ethically desirable. For example, research on those with intellectual disabilities has demonstrated the extent to which their health care needs are not being met.<sup>46</sup>

3. How will the chosen variables' strengths and weaknesses for evidence gathering and analysis affect ethical issues? Undesirable ethical consequences do not arise only as a result of changes in broader understandings of the populations being studied. Choosing variables for evidentiary reasons can result in real-world effects, which may themselves be ethically desirable or undesirable (and frequently contain elements that are both). For example, the use of area-based deprivation measures can result in changes to funding allocations that have both desirable and undesirable consequences, including shaping future interventions and policy (illustrated in Table 1).
4. How will the chosen variables' ethical strengths and weaknesses affect evidence gathering and analysis? The ethical consequences of current public health research or practice could result in further lines of inquiry being jeopardized or facilitated. For example, those who research race must be cautious to avoid stigmatizing racial groups, as stigmatization can lead to people reporting 1 race or ethnicity while privately identifying with a different race or ethnicity.<sup>47</sup>

These questions can help begin the journey of bringing together epistemic and ethical issues in public health. However, the process of performing coupled ethical–epistemic analysis benefits from multidisciplinary collaborations that include ethicists and community stakeholders. Further work is required to take this agenda forward.

## CONCLUSIONS

Some categorizations of exposure variables in etiological research and practice imply causal effects in a manner that may ultimately stigmatize vulnerable populations, thereby exacerbating health inequities and hence working against a central goal of public health.

Therefore, greater care when theorizing variables is needed, as is more explicit differentiation between proxy exposure variables and the causal factors that are actually of interest. We have described and applied a coupled ethical–epistemic framework for considering these issues to the cases of US blood donation policy and health disparities research in Scotland. ■

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