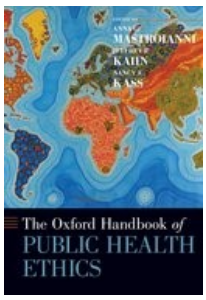

The Oxford Handbook of Public Health Ethics

Anna C. Mastroianni (ed.) et al.

https://doi.org/10.1093/oxfordhb/9780190245191.001.0001

Published: 2019 **Online ISBN:** 9780190245207 **Print ISBN:** 9780190245191

CHAPTER

29 Framing Public Health Research Ethics

Holly A. Taylor

https://doi.org/10.1093/oxfordhb/9780190245191.013.29 Pages 331–341

Published: 14 March 2019

Abstract

The systematic collection and analysis of data is central to public health. Some public health activities are easily classified as either research or nonresearch, while the distinction is more nuanced for other activities. How an activity gets classified has ethical implications—additional oversight, requirements for consent of participants, and potentially whether the activity can be undertaken at all. Scholarly analysis of this issue suggests that an important aspect distinguishing research from other public health data collection activities is to consider the intent of the activity and whether experimentation is involved. The three ethical principles of respect for persons, beneficence, and (distributive) justice guide researchers in their relationships with individual participants. Because public health research can be directed at an entire community, this chapter posits that these three principles must be extended to appropriately include and consider the community as a stakeholder.

Keywords: public health research, community, public health ethics, respect for persons, beneficence, justice, consent

Subject: Social and Political Philosophy, Moral Philosophy, Philosophy

Series: Oxford Handbooks

Collection: Oxford Handbooks Online

p. 331

Introduction

THE mission of public health is "assuring conditions in which people can be healthy," through its core functions of "assessment, policy development, and assurance" (IOM, 1988, 7). The systematic collection and analysis of public health data is central to this assessment function and spans a number of activities, including "surveillance, identifying needs, analyzing the causes of problems, collecting and interpreting data, case-finding, monitoring and forecasting trends, research, and evaluation of outcomes" (IOM, 1988, 44). Thus, data are collected and analyzed in the context of public health practice, such as ongoing infectious disease surveillance to detect epidemics, or in the context of frank research, such as studies designed to better understand the causes and preventability of infectious disease. The goal of this chapter is to offer a framing of the ethics of the latter, *public health research.*

Some public health activities are easily classified as either research or nonresearch, while the distinction for other activities is more nuanced and classification becomes more challenging. How an activity gets classified has ethical implications—additional oversight, requirements for consent of participants, and potentially whether the activity can be undertaken at all. One way to frame the ethics of public health research is to distinguish it from public health practice. While public health professionals engaged in systematic data collection in support of public health practice activities are subject to professional codes of ethical conduct, the conduct of public health research is subject to an additional set of ethical principles as well as regulations (National Commission, 1979; Public Health Leadership Society, 2002; Soskolne, 1991, 1997; Coughlin, Beauchamp, and Weed, 2009; Coughlin, 2009). The research-practice distinction is
p. 332 ethically important, ↳ because in the conduct of public health practice the needs of the public can override the rights of the individual, which is much more difficult to defend in the context of research. For example, public health mandates to collect, report, and share identifiable information potentially infringe individual autonomy but are justified by the expected benefit to the public's health. In contrast, the conduct of public health research must respect the rights of individual participants (e.g., through practices such as informed consent), despite the potential benefit to the public. Public health research is also subject to the ethical principles of human subject research and is likely to be subject to regulatory review and oversight. The three principles informing the ethics of human subject research—respect for persons, beneficence, and justice (specifically distributive justice, rather than other types of justice)—guide researchers in carrying out their research (e.g., seeking informed consent from participants, minimizing risk of harms and maximizing the likelihood of potential benefits, and engaging in fair recruitment practices) (National Commission, 1979). This chapter begins by examining various attempts to distinguish public health research from practice, and it highlights the ethical implications of both.

Practitioners often work for local and state agencies responsible for the protection and promotion of the health of their communities. In the context of public health practice, *community* refers to the citizens of the local jurisdiction for which the local public health agency is responsible. How, though, should researchers account for community in the context of the ethics of public health research? The standard formulation of human subject research fails to account for community: the stakeholders are the researcher, the participant, and society; or, rather, the researcher recruits participants to generate knowledge to benefit society broadly. A conventional application of research ethics principles to public health research may fail to account for risks and benefits to the community in which the research is being conducted, resulting in avoidable harm to the community. The second part of this chapter contends that the ethics of public health research must be framed to include the community perspective (i.e., traditional ethics principles must be extended to include the community as a key stakeholder in the conduct of public health). The community, in this framing, deserves respect and ought to be protected from harm and exploitation, and benefits to the community should be maximized.

Distinguishing Public Health Research from Practice

Public health practice involves the systematic collection of data to protect and promote the health of the public. Public health practitioners must strike a balance between the private nature of the data they collect and the benefit to the population whose health the data is meant to protect and promote. Codes of ethics are directed at helping public health practitioners navigate this balance. In the United States, two relevant
p. 333 principles from the Public Health Leadership Society's *Principles of the Ethical Practice of Public* ↳ *Health*, adopted as the standard for public health practitioners by the American Public Health Association, serve as examples:

> "Public health should achieve community health in a way that respects the rights of individuals in the community .... Public health institutions should protect the confidentiality of information that can bring harm to an individual or community if made public. Exceptions must be justified on the basis of the high likelihood of significant harm to the individual or others."
>
> (Public Health Leadership Society, 2002, 4)

Public health surveillance is a prototypical example of the systematic collection of public health data. A close examination reveals what is at stake in striking the right balance between individual rights to privacy and what is best for the health of the community.

The goal of public health surveillance is to identify and track trends to guide and target public health interventions. It can include the collection of identifiable information to pinpoint the source of disease (see "Public Health Surveillance: Ethical Considerations," this volume). In the United States, for example, health care providers and laboratories are required by state law to report cases of sexually transmitted infection (STI) to public health authorities. An individual seeking STI testing will be informed that positive results will be reported to public health authorities. So while the individual's testing decision is voluntary, the health care provider's reporting of the individual's results is mandatory, and may also result in additional individual follow-up and contact of sexual contacts. In this example, the public health mandate of reporting is justified by the benefit to the community, even though the practice conflicts with both the self-determination of and the protection of private information about the tested individual.

Identifiable information is collected to make sure that the individual diagnosed with the STI is connected to appropriate care, and that those who may have been exposed to infection are notified (Faden, Kass, and Powers, 1991). The burden of inclusion in public health surveillance efforts (i.e., the risk of a potential breach of confidentiality) falls on a particular group of individuals—in this case, those diagnosed with an STI. An individual experiencing the symptoms of an STI could choose to avoid testing to avoid the reporting of the diagnosis, but the individual would then be forgoing referral for treatment. In some instances, states have conditionally mandatory testing programs for STIs to facilitate testing and diagnosis (Faden, Kass, and Powers, 1991). While many, if not all, of those diagnosed with an STI will directly benefit as a result of being tested, the goal of this public health surveillance activity is to benefit the broader community by preventing the further spread of the STI (Fairchild and Bayer, 2004; Taylor and Johnson, 2007; Public Health Ontario, 2012). This balance in favor of the health of the population is common to much of public health practice. For example, school-age children in the United States are subject to state vaccination mandates, and individuals presumed to have a highly contagious disease can be isolated or quarantined (Bensimon and Upshur, 2007; Omer et al., 2009).

Public health practice is most often carried out by public health practitioners affiliated with local public
p. 334 health agencies. Public health research, on the other hand, can ↳ be conducted by public health practitioners as well as by independent public health investigators (e.g., those affiliated with an academic institution or nongovernmental organization). In the same way that public health practitioners are subject

to codes of ethical conduct, public health researchers are held to professional codes regarding the responsible conduct of (all) research (National Academy of Sciences, 2009). When practitioners or researchers are engaged in public health research involving human subjects, they are also subject to policy oversight informed by the principles relating to the ethics of research on human subjects as articulated in the *Belmont Report* (National Commission 1979; HHS, 2017). Regulations include requirements for independent review of the proposed research and informed consent from those asked to supply data. Clear distinctions between public health research and practice are necessary to avoid misclassifications that could hamper or limit the collection of critical public health information, on the one hand, or fail to require oversight and consent of participants, on the other. Clear definitions are essential for guiding public health activities and for helping public health practitioners and researchers appropriately balance the interests of the individuals, groups, and communities the activities are intended to serve or benefit.

Given the implications of whether systematic data collection is defined as public health practice or public health research, numerous authors have proposed criteria to distinguish the two (NBAC, 2001; Amoroso and Middaugh, 2002; Hodge and Gostin, 2004; Hodge, 2005; Taylor and Johnson, 2007; CDC, 2010; Otto, Holodniy, and DeFraites, 2014; Barrett et al., 2016). The two most common and promising criteria among those proposed are the intent of the public health activity and whether the activity involves experimentation. Each of these criteria is discussed further below.

Intent

Numerous authors and the US Centers for Disease Control and Prevention (CDC) conclude that the *intent* of systematic public health data collection is the core consideration for determining whether the activity is public health practice or public health research (CDC, 1999, 2010; Hodge and Gostin, 2004; Otto, Holodniy, and DeFraites, 2014). The argument is that the intent of systematic public health data collection is to "assure conditions in which people can be healthy," while the intent of human subject research is to contribute to generalizable knowledge (IOM, 1988; NBAC, 2001; CDC, 2010; Otto, Holodniy, and DeFraites, 2014).

Another way to consider the intent of systematic public health data collection is through recognition of the actor collecting the data: public health data is most often collected by local authorities. Local public health authorities serve local jurisdictions and are ethically obligated to protect the health and safety of their local communities. Thus, the intent of local public health data collection is to promote the health of those who reside in the local jurisdiction, (i.e., everyone in the local community). The intent of public health research, on the other hand, is to contribute to generalizable knowledge (i.e., the ethical obligation of the public health researcher is to the health and safety of the research participants). Research participants may be
p. 335 members of a local community, but the ↳ researcher is ethically obligated to protect the health and safety only of those enrolled in their research. The knowledge generated by public health research *could be* applied to and benefit those living in the local community from which the subjects were recruited, but the intent of the effort is to contribute generalizable knowledge that may be useful beyond the local community. When the intent of the systematic public health data collection is to benefit those beyond the borders of the local jurisdiction, it is then classified as public health research. Indeed, the risk-benefit assessment required when conducting human subject research allows for the potential risks to individual participants to be offset by benefits to society (National Commission, 1979). For example, if a public health research project was conducted in the City of Baltimore, the potential risks to those enrolled may be offset by the potential benefit that may accrue to those who reside in similar cities.

Experimentation

Whether experimentation is a component of systematic public health data collection is another criterion that authors have proposed as a way to distinguish public health practice from public health research (Hodge and Gostin 2004; Taylor and Johnson, 2007; Otto, Holodniy, and DeFraites, 2014). Experimentation can be defined to include the exposure of an individual or community to an activity not yet proven effective (i.e., not yet standard practice). In general, public health practice does not include experimentation. Public health practice utilizes standard interventions previously proven effective to prevent disease and promote health. While there may be some risk to the individuals or communities exposed to a standard public health intervention, the intended, known benefits of the intervention outweigh the potential risk. Testing a novel public health intervention where individuals or groups of individuals may be exposed to risk ought to be tested against the standard intervention (or placebo if no standard exists) before it is adopted more broadly. It is in the testing of a novel intervention that the ethics of human subject research become relevant. It would be unethical to expose an individual or group of individuals to a public health intervention with known risks and unknown potential benefit without their informed consent.

Knowing the intent of systematic data collection activity and whether experimentation is involved are key to distinguishing public health practice from research. While these two criteria on their own may not be adequate to accurately classify every proposed systematic data collection activity as practice or research, they narrow the number of projects about which practitioners, researchers, and oversight bodies are uncertain.

Community as Stakeholder

The Belmont principles of respect for persons, beneficence, and justice are most easily applied by those conducting conventional biomedical and behavioral research (National Commission, 1979). The term
p. 336 *conventional* is meant to refer to research conducted to ↳ determine whether a novel intervention is as good as or better than the standard intervention (or placebo if no standard exists). An investigator formulates a research question, recruits individual participants to participate, and collects data with the intent of generating findings to benefit future patients. The Belmont principles help the investigator to navigate how to obtain informed consent from potential participants, how to strike an appropriate balance between the benefits and risks to the participants enrolled and to future patients, and to assure that the benefits and risks of participation are fairly distributed among those who participate. A number of authors endorse holding public health research to these principles but find the principles wanting in their failure to consider the community as a key stakeholder in research (Taylor and Johnson, 2007; Verweij and Dawson, 2009; Barrett et al., 2016; Taylor et al., 2016). Failing to consider the community as a key stakeholder in the conduct of public health research may result in ethical harms that could otherwise be avoided. What follows is a proposal that the Belmont principles of respect for persons and beneficence can be extended to accommodate the community as a stakeholder.

Respect for Persons/Respect for Community

One way to ensure that the interests of the community are considered in the ethical evaluation of a public health research project is to extend the principle of respect for persons to encompass the community as a stakeholder (National Commission, 1979; Public Health Ontario, 2012; Taylor et al., 2016). Such an extension places an affirmative obligation on the public health researcher(s) to acknowledge the community as a key stakeholder in the proposed research and respect the community when considering how best to seek permission to include the community as a participant in research. The community in this formulation is an identifiable group that has a stake in the conduct of the proposed research. The community is the group from which the participants will be drawn (i.e., eligible by virtue of their membership in the community) and may be affected by the outcome of the research. While a community can be defined by a variety of borders, whether geographic, cultural, racial, or another classification, it does have recognizable borders. Nonetheless, engagement with "the community" is not without challenges, including determining those boundaries and identifying who is authorized to represent the values and beliefs of the community. Taylor et al. (2016) conclude that, at a minimum, public health researchers must inform the community of their presence and intent and disseminate the findings of the research conducted. That is, disclosure, rather than informed consent, is required, and findings are disseminated out of respect for the community's contribution to the research effort. Community-based participatory research (CBPR) engages the community as an active partner from the development of the research question through to how the results ought to be disseminated (Israel et al., 2005; see also "Community-Based Participatory Research: Ethical Considerations," this volume). Public health researchers who engage in CBPR are held to a higher ethical standard regarding their obligation to engage with the community as a stakeholder. In practical ↳ terms, this disclosure may take a variety of forms. In some cases, a community has a
p. 337
recognizable leader or set of leaders who must be approached first to gain access to the larger community. While the permission of the leader is important, respect for community does not mean the investigator should not also obtain informed consent from the individuals approached to participate. An ethically acceptable exception to this rule may be when a researcher is engaged in a cluster randomized trial (CRT).

A CRT is designed to study an intervention's effects on identified groups or populations rather than individuals. Randomization is accomplished at the level of communities. CRTs are commonly used to test the effect of an intervention to increase awareness about a particular health risk (Barrett et al., 2016). For example, one community may be targeted for a media campaign, while no such campaign is used in a different but comparable community. The research is designed to compare differences in subsequent awareness of the health risk. Investigators identify eligible communities, meant to be geographically distant in order to minimize "contamination" across communities, and randomly assign them to receive or not receive the novel intervention. Data are collected on awareness in all communities, and the outcomes are compared.

Seeking individual consent in this example would likely be resource-intensive, as well as likely to undermine the ability of the investigators to answer their research question when and if people choose not to participate. Under such circumstances, the investigator might seek the option to waive individual consent and propose engaging in a community consultation in advance of the study, the goal of which would be to disclose their presence and intent as well as seek permission to engage the community. As noted above, at the very least the study team would need to seek permission from the relevant authorities to collect data in the study communities, and be prepared to justify their presence in each community during the data collection phases of the project. Whether or not such an approach would be considered ethically acceptable would likely hinge on the risk of the intervention, the type and magnitude of the data collected from community members, and the dissemination plans of the investigators (Taylor and Johnson, 2007; Taylor et al., 2016).

Risks and Potential Benefits to Communities

The ethical principle of beneficence can also be extended to consider the community as a stakeholder in research. The principle of beneficence requires that researchers "do no harm and maximize possible benefits and minimize possible harms" (National Commission, 1979). Because some research must expose participants to risk in order to answer an important research question, investigators must carefully consider the balance of potential benefits and harms. The principle of beneficence can and should be extended to the community as a stakeholder. The practical application of the principle of beneficence is to identify the potential risks to which research participants may be exposed, the potential benefits that may accrue to participants, and the benefits that may accrue to future patients or society. Once identified, the investigator must consider ↳ whether potential benefits to the individual and society outweigh the potential risks to the individual participants. Verweij and Dawson (2009) note that the utility of beneficence is limited in the conduct of public health research if it is not extended to the potential risks that may accrue to the community from which the research participants are drawn. Extending the risk assessment beyond the individual participants may result in the identification of community-wide harms such as stigma or economic loss. Failure to acknowledge that the community may be at risk can foster mistrust of investigators and compromise the research enterprise beyond the particular project being conducted (Public Health Ontario, 2012; Pacheco et al., 2013; Taylor et al., 2016).

p. 338

For example, researchers involved in public health research projects that use media campaigns must consider the risk of harm such campaigns may bring to the community. A media campaign meant to encourage good dental hygiene is different from a media campaign to prevent human immunodeficiency virus (HIV) infection or interpersonal violence. An HIV or violence prevention media campaign, for example, should consider the potential for harm to communities, including the potential association of the research or its findings with public assumptions that the participating communities are at high risk for HIV or have a high prevalence of interpersonal violence. The potential for such assumptions should not mean the research ought not to go forward, but rather that researchers consider the potential harm to communities in balancing research risks and benefits, and consider approaches to appropriately managing it, for example by disclosure to the community prior to implementing the research. Indeed, the community may endorse research on the understanding that the potential benefits it offers to the community, as well as to broader society, sufficiently outweigh the potential risks of community-level harm.

Justice/Social Justice

The principle of justice as articulated in the *Belmont Report* is a principle of distributive justice (National Commission, 1979), which demands that an investigator and the oversight process assure that the burdens and benefits of participation in research are allocated fairly, through equitable selection and participation of participants and the groups they are deemed to represent. Since the publication of the *Belmont Report*, the understanding of the principle of justice has been expanded to include the consideration that groups ought not to be excluded from the potential benefits of participation in research (Mastroianni and Kahn, 2001).

Attention to distributive justice in the conduct of public health research is essential. Public health researchers must make sure that particular groups are not excluded arbitrarily from participation, and at the same time ensure that particular groups do not take on more than their fair share of the burden of research participation (National Commission, 1979; Mastroianni and Kahn, 2001). An extension of distributive justice to the community as stakeholder could bring attention to whether a particular community (or communities) is bearing more than its share of the burdens of research. This question ↳ is relevant to at least two kinds of public health research. The term *parachute research* refers to research where the investigator may drop into a community to collect biological samples and leave as soon as the data collection is complete, never to return to the community (Flicker et al., 2007). Longitudinal epidemiologic

p. 339

cohort studies may also place burdens on the communities in which they are conducted. Such studies are ethically acceptable if the community bears some benefit from the presence of the study. For example, a community may benefit if its clinical infrastructure is enhanced by raising the level of health care received.

In addition to reflecting on how the principle of justice can be extended to acknowledge the community as a stakeholder, Verweij and Dawson (2009) and Taylor et al. (2016) argue that the ethical conduct of public health research should attend to social justice. Powers and Faden (2006) argue that attention to the least advantaged is a "hallmark of public health" and among the fundamental aims of public health research. By extension, public health researchers ought to also attend to health inequities while focusing on health promotion and the prevention of disease (i.e., those differences in health status that result from unfair institutional arrangements rather than biology) (Taylor et al., 2016). Two ways to make this attention to social justice real would be to engage in public health research designed to identify barriers and facilitators to health equity or to prioritize the public health needs of the most disadvantaged (Public Health Ontario, 2012).

Conclusion

Whether an activity is considered public health practice or public health research has important ethical implications, including additional oversight such as prospective approval, and requirements for consent, of participants. The criteria of intent of the activity and whether it is experimentation are useful factors for helping to distinguish public health practice from public health research, though it is difficult to prevent some public health practice activities from being misclassified as research and some research activities misclassified as practice.

The principles relevant in the conduct of research on human subjects—respect for persons, beneficence, and justice—are applicable but not sufficient in consideration of the ethics of public health research. The additional principle of community is a critical and necessary addition. The so-called Belmont principles were drafted in response to a series of ethical violations that resulted in direct harm to and exploitation of research subjects (National Commission, 1979). In retrospect, it makes sense that the community was not acknowledged as a stakeholder in the conduct of human research, given the attention the principles bring to the need to protect vulnerable populations. The focus of the Belmont principles was on the recruitment of competent adults able to make informed decisions about enrollment in research that may put them at risk of harm but meant to benefit them or future patients. Extending the principles to accommodate the
p. 340 community as a stakeholder will bring attention to the interests of the community and ↳ require that public health researchers consider the implications of their work beyond the individuals they approach to enroll. Such an extension may also encourage researchers to engage more directly with the communities whose health they want to protect and promote.

References

Amoroso P. J., and Middaugh J. P. 2002. “Research vs. Public Health Practice: When Does a Study Require IRB Review?” *Preventive Medicine* 36: 250–253.
Google Scholar WorldCat

Barrett, D. H., Brown, N., DeCausey, B. R., Saenz, C., and Dawson, A. 2016. “Public Health Research.” In *Public Health Ethics: Cases Spanning the Globe*, edited by D. H. Barrett, L. H. Ortmann, A. Dawson, C. Saenz, A. Reis, and G. Bolan (Cham, Switzerland: Springer International). http://www.springer.com/us/book/9783319238463.
Google Scholar Google Preview WorldCat COPAC

Bensimon, C. M, and Upshur, R. E. G. 2007. “Evidence and Effectiveness in Decision-Making for Quarantine.” *American Journal of Public Health* 97(Suppl. 1): S44–S48.
Google Scholar WorldCat

CDC (Centers for Disease Control and Prevention). 1999. *Guidelines for Defining Public Health Research and Public Health Non-Research* (Atlanta: CDC). https://www.cdc.gov/od/science/integrity/docs/defining-public-health-research-non-research-1999.pdf.
Google Scholar Google Preview WorldCat COPAC

CDC (Centers for Disease Control and Prevention). 2010. *Distinguishing Public Health Research and Public Health Non-research* (Atlanta: CDC). https://www.cdc.gov/od/science/integrity/docs/cdc-policy-distinguishing-public-health-research-nonresearch.pdf.
Google Scholar Google Preview WorldCat COPAC

Coughlin, S. S., ed. 2009. *Ethics in Epidemiology and Public Health Practice*. 2nd ed. (Washington D.C.: American Public Health Association).
Google Scholar Google Preview WorldCat COPAC

Coughlin, S. S., Beauchamp, T. L., and Weed D. L., eds. 2009. *Ethics and Epidemiology*. 2nd ed. (New York: Oxford University Press).
Google Scholar Google Preview WorldCat COPAC

Faden, R. R., Kass, N. E., and Powers, M. 1991. “Warrants for Screening Programs: Public Health, Legal and Ethical Frameworks. “In *AIDS, Women and the Next Generation: Towards a Morally Acceptable Public Policy for HIV Testing of Pregnant Women and Newborns*, edited by R. R. Faden, G. Geller, and M. Powers, 3–26 (New York: Oxford University Press).
Google Scholar Google Preview WorldCat COPAC

Fairchild, A., and Bayer R. 2004. “Ethics and the Conduct of Public Health Surveillance.” *Science* 303(5658): 631–632.
Google Scholar WorldCat

Flicker, S., Travers, R., Guta, A., McDonald, S., and Meagher, A. 2007. “Ethical Dilemmas in Community-Based Participatory Research: Recommendations for Institutional Review Boards.” *Journal of Urban Health* 84(4):478–493.
Google Scholar WorldCat

HHS (US Department of Health and Human Services). 2017. “45 CFR 46: Protection of Human Subjects.” https://www.hhs.gov/ohrp/regulations-and-policy/regulations/45-cfr-46/.
WorldCat

Hodge, J. G. 2005. “An Enhanced Approach to Distinguishing Public Health Practice and Human Subjects Research.” *Journal of Law, Medicine & Ethics* 33(1): 125–141.
Google Scholar WorldCat

Hodge, J. G., and Gostin L. O. 2004. *Public Health Practice vs. Research: A Report for Public Health Practitioners Including Cases*

and Guidance for Making Distinctions (Atlanta: Council of State and Territorial Epidemiologists). http://www.cste2.org/webpdfs/CSTEPHResRptHodgeFinal.5.24.04.pdf.
Google Scholar Google Preview WorldCat COPAC

IOM (Institute of Medicine). 1988. *The Future of Public Health* (Washington, D.C: National Academies Press).
Google Scholar Google Preview WorldCat COPAC

Israel, B., Eng, E., Schulz, A. J., and Parker, E. A., eds. 2005. *Methods in Community-Based Participatory Research for Health* (San Francisco: Jossey-Bass).
Google Scholar Google Preview WorldCat COPAC

Mastroianni, A., and Kahn J. 2001. "Swinging on the Pendulum: Shifting Views of Justice in Human Subjects Research." *Hastings Center Report* 31(3): 21–28.
Google Scholar WorldCat

National Academy of Sciences. 2009. *On Being a Scientist: A Guide to Responsible Conduct in Research*. 3rd ed. (Washington, D.C.: National Academies Press) https://www.nap.edu/catalog/12192/on-being-a-scientist-a-guide-to-responsible-conduct-in.
Google Scholar Google Preview WorldCat COPAC

National Commission (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research). 1979. *The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research* (Washington, D.C.: US Department of Health, Education, and Welfare). https://www.hhs.gov/ohrp/regulations-and-policy/belmont-report/index.html.
Google Scholar Google Preview WorldCat COPAC

NBAC (National Bioethics Advisory Commission). 2001. *Ethical and Policy Issues in Research Involving Human Participants* (Bethesda, Md.: NBAC) https://bioethicsarchive.georgetown.edu/nbac/human/overvol1.pdf.
Google Scholar Google Preview WorldCat COPAC

Omer, S. B., Salmon, D. A., Orenstein, W.A., DeHart, P., and Halsey, N. 2009. "Vaccine Refusal, Mandatory Immunization, and the Risks of Vaccine-Preventable Diseases." *New England Journal of Medicine* 360(19): 1981–1988.
Google Scholar WorldCat

Otto, J. L., Holodniy, M., and DeFraites, R. F. 2014. "Public Health Practice Is Not Research." *American Journal of Public Health* 104(4): 596–602.
Google Scholar WorldCat

Pacheco, C. M, Daley, S. M., Brown, T., Filippi, M., Greiner, K. A., and Daley, C. M. 2013. "Moving Forward: Breaking the Cycle of Mistrust between American Indians and Researchers." *American Journal of Public Health* 103(12): 2152–2159.
Google Scholar WorldCat

Powers, M., and Faden, R. 2006. *Social Justice: The Moral Foundations of Public Health and Health Policy* (New York: Oxford University Press).
Google Scholar Google Preview WorldCat COPAC

Public Health Leadership Society. 2002. *Principles of the Ethical Practice of Public Health, Version 2.2*. https://www.apha.org/-/media/files/pdf/membergroups/ethics/ethics_brochure.ashx?la=en&hash=1E9425A9C96347E42AC0D6B0D2000AA6A8717C3C.
Google Scholar Google Preview WorldCat COPAC

Public Health Ontario. 2012. *A Framework for the Ethical Conduct of Public Health Initiatives* (Ontario: Public Health Ontario). https://www.publichealthontario.ca/en/eRepository/PHO%20%20Framework%20for%20Ethical%20Conduct%20of%20Public%20Health%20Initiatives%20April%202012.pdf.
Google Scholar Google Preview WorldCat COPAC

Soskolne, C. 1991. “Ethical Decision Making in Epidemiology: A Case Study Approach.” *Journal of Clinical Epidemiology* 44(Suppl. 1): 125S–130S.
Google Scholar WorldCat

Soskolne, C. 1997. “Ethical, Social, and Legal Issues Surrounding Studies of Susceptible Populations and Individuals.” *Environmental Health Perspectives* 106(Suppl. 4): 837–841.
Google Scholar WorldCat

Taylor, H. A., McGee, S. J., Faden, R. R., and Kass, N. 2016. “Ethics of Public Health Research: Moral Obligations to Communities.” In *International Encyclopedia of Public Health*, edited by K. Heggenhougen and S. Quah, 423–427 (Amsterdam and Boston: Elsevier).
Google Scholar Google Preview WorldCat COPAC

Taylor, H. A., and Johnson, S. 2007. “Ethics of Population-Based Research.” *Journal of Law Medicine and Ethics* 35(2): 295–299.
Google Scholar WorldCat

Verweij, M., and Dawson, A. 2009. “Public Health Research Ethics: A Research Agenda.” *Public Health Ethics* 2(1): 1–6.
Google Scholar WorldCat