



Genomics and the Public Health Code of Ethics

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We consider the public health applications of genomic technologies as viewed through the lens of the public health code of ethics. We note, for example, the potential for genomics to increase our appreciation for the public health value of interdependence, the potential for some genomic tools to exacerbate health disparities because of their inaccessibility by the poor and the way in which genomics forces public health to refine its notions of prevention.

The public health code of ethics sheds light on concerns raised by commercial genomic products that are not discussed in detail by more clinically oriented perspectives. In addition, the concerns raised by genomics highlight areas of our understanding of the ethical principles of public health in which further refinement may be necessary. (*Am J Public Health*. 2005;95:2139–2143. doi:10.2105/AJPH.2005.066878.)

IN RECENT YEARS, A PUBLIC

health ethic has been distinguished from medical ethics.^{1–3} Public health has been defined as what society does collectively to ensure that conditions exist for people to be healthy.⁴ In public health ethics, the key relationship is between a government agency, such as a local health department, and the population it serves, whereas, in medicine,

the physician–patient relationship is the basis of most ethical questions. While medical ethics often deal with the application of technologies to the beginning and end of life, ethical questions in public health often address the tension between the rights of individuals and the good of the overall community, democratic processes in determining health policies, the prevention of conditions that lead to poor health, and the protection of disenfranchised or marginalized populations. Contemporary discussions of public health ethics occur most often in the areas of HIV/AIDS, health disparities, and genomics.

Genomics is the study of the functions and interactions of all the genes in the genome, including their interactions with environmental factors.⁵ The ethical concerns in genomics are well-developed enough to have their own acronym, ELSI, which stands for the ethical, legal, and social implications.⁶ The National Institutes of Health (NIH) has a National Genome Research Institute that includes the study and dissemination of ethical implications (<http://www.nhgri.nih.gov/PolicyEthics>). Genomics ELSI resource centers have been made available by the Centers for Disease Control and Prevention (<http://www.cdc.gov/genomics/links/ethical.htm>) and the World Health Organization (<http://www.who.int/genomics/elsi/en>).

An underdeveloped topic in ELSI discussions is how medicine and public health might approach ethical questions differently. For example, one of the principles that is fundamental in medical ethics but subject to more contingencies in public health is autonomy. Because a physician has high social status and access to protected resources that may cure or harm, it is important to protect the patient from potential abuse and to guard his or her autonomy. But public health entails relationships between individuals in society as well as the relationship between the population and health agencies. In a community, 1 person's actions can affect other people; one person's infection can be another person's exposure. In such instances, personal autonomy must be constrained for the social good. Thus, a principle that is fundamental in public health ethics is interdependence. This principle can have important implications for ethical perspectives on the applications of genomic tools.

ARTICULATING A PUBLIC HEALTH ETHIC

Although interdependence has been evident in public health law and practice for centuries, only recently has interdependence been articulated as a fundamental value in public health ethics. This was made explicit by the Public Health Code of Ethics,

which was endorsed by the American Public Health Association in 2002.³ The code consists of 12 ethical principles, notes on the 12 principles, and 11 underlying values and beliefs inherent to a public health perspective. (They are posted on the World Wide Web at <http://www.phls.org/products.htm> and <http://www.apha.org/codeofethics>.) The code does not prescribe narrow actions but aims to help policy-makers address a full range of questions that are important in the ethical practice of public health. Using the code in this way should also raise the level of discussion about ethical issues, promoting more informed and less superficial debates.

With this end in mind, we examine the application of genomics to public health as viewed through the lens of the 12 principles of the Public Health Code of Ethics. We do not generate an exhaustive list of issues but instead provide examples produced by a public health ethics perspective.

THE PUBLIC HEALTH CODE OF ETHICS

Following are the 12 principles of the Public Health Code of Ethics, along with a brief discussion of the concerns about genomics produced by each principle.

1. Public health should address principally the fundamental causes



of disease and requirements for health, aiming to prevent adverse health outcomes.

This principle was written with a view toward the underlying causes of disease, such as the mining industry labor policies that facilitated the spread of tuberculosis in South Africa, as described in the book *White Plague, Black Labor*.⁷ But genomics sheds new light on the idea of fundamental causes. DNA is popularly conceived of as the blueprint of life, what could be more fundamental?

Will policymakers shift funding from social and environmental factors affecting disease to genetic factors? Most diseases result from not just 1, but many factors that range from the biological to the social, the molecular to the environmental. Thus, public health ethics needs to consider the degrees to which genetics can be construed to be, and is popularly perceived as, fundamental. Clarity on this issue is imperative if the public health community is to stand against the tide of other fundamental forces—namely, populist notions of genetic determinism, our love of technological fixes, and industrial forces that see a sizeable profit in genomic tools.

2. Public health should achieve community health in a way that respects the rights of individuals in the community.

This principle highlights the tension between individual rights and the good of the community, which is so often at the root of ethical decisions in public health. The wording communicates that, in public health, the starting

place is the good of the community. Genomics can provide us with a new appreciation of the interdependence of people that distinguishes a community from a number of unconnected individuals. A comparison of genes shows how some labels used to create divisions between people have no biological basis.⁸ For example, Lewontin reported that within-group genetic variation is much greater than the variation seen between racial groups. The implication of Lewontin's results is that race statistically explains only a small proportion of genetic variations (e.g., blood group variation between races statistically accounts for about 6% of the total variation).⁹ Typically, these variations are better explained by geographic distance.¹⁰

It is important that individuals maintain the right to informed consent regarding the use of a genetic test. This right was abused in 2000 by the Burlington Northern Santa Fe Railroad Company. The company assumed that carpal tunnel syndrome had a genetic basis and subjected employees claiming to suffer from the syndrome to a nonconsensual genetic test in order to deny workers' compensation to those who tested positive.^{11,12}

3. Public health policies, programs, and priorities should be developed and evaluated through processes that ensure an opportunity for input from community members.

When there is a decision to be made about the use of a genomic tool, who makes the decision? Perhaps it is a decision about the use of Medicaid funds

for a particular genetic test or product. The idea behind the third principle in the Public Health Code of Ethics is that people and communities should have some say in the policies that affect them. This principle might track its lineage to the early American objection to taxation without representation.

To engage in a discussion of the application of genomic technologies, a community must be well informed. We pursue this concern in discussing ethical principle 6. Another question raised by this principle is who constitutes the relevant community, or who can represent the community? Because public health clinics primarily serve the poor, many practitioners in public health are likely to imagine a low-income mother of young children as the prototypical community member who should have some say about public health policies and programs. Ethical principle 4 reinforces this impulse. Moreover, although such concepts as "the African American community" or "the Native American community" push the limits of what can be reasonably regarded as a community, the underrepresentation of such groups in the scientific disciplines that develop and apply genomics will limit the ability of public health institutions to ethically develop policies, programs, and priorities pertaining to genomics.

4. Public health should advocate for, or work for the empowerment of, disenfranchised community members, ensuring that the basic resources and conditions

necessary for health are accessible to all people in the community.

This ethical principle concedes that public health cannot provide all people with the level of health resources available to the wealthy. What are the basic resources necessary for health when it comes to genomic technology? Perhaps the diseases for which there are tests but no treatments would be outside the minimum standard. Such is the case with Huntington's disease. Other criteria might be the proportion of the population that would benefit, the accuracy of the test, the efficacy and availability of the treatment, and the cost of testing and treatment compared with other potential uses of the public health dollars required to make the genomic tools available.

Furthermore, who are the disenfranchised with respect to genomics and how does one empower them? Are the disenfranchised those who might be stigmatized by the results of a genomic test and discriminated against? Or are they the ones who cannot afford a test or treatment? Does empowering mean enabling them to argue for their right not to be tested or to gain access to a particular technology available only to the wealthy? If so, this principle could discourage people from setting their personal interests aside for the good of the community, thus putting it in conflict with principle 2. On the other hand, empowerment may consist of enabling individuals to understand the genomic technologies, to recognize how to think about them in terms of the good of the



whole community, and to enable them to participate in community discussions on the topic.

The opposite of this form of empowerment would be eugenic measures by which individuals with certain characteristics are either killed, sterilized, or forced to have an abortion in order to eliminate or prevent the birth of people with the unwanted characteristic. We may wish to think that humanity has advanced beyond such uses of genetic information. But there are people alive today who have witnessed or experienced such procedures based on characteristics assumed to be hereditary. They include survivors of the genocide of the Nazi regime and those among the 7600 or more North Carolinians who received forced sterilization as part of the state's eugenics program, which operated from 1934 to 1974.¹³

5. Public health should seek the information needed to implement effective policies and programs that protect and promote health.

Our ability to develop technologies and design new genetic tools far outpaces our evaluation of the efficacy and effectiveness of the tools, as well as the development of related preventive measures or treatments. Too often, conjecture rather than a systematic assessment is used to argue for the utility of a tool. However, the need for thorough evaluation of each new genetic test could require a large proportion of the funds available for health research, an amount disproportionate to the percentage of people that would benefit from them. The number who would benefit

would often be miniscule compared with those who would benefit from other health-related research. How much of the research on, say, an AIDS vaccine should be diverted to evaluation of new genomic technologies unrelated to AIDS? Thus, the value of the research that would not occur because funding is diverted needs to be weighed against the potential gains from the genomic research. In the meantime, public health ethics would argue against the use of public funds to provide any genomic technologies that have not been appropriately evaluated.

6. Public health institutions should provide communities with the information they have that is needed for decisions on policies or programs and to obtain the community's consent for their implementation.

When the utility of a technology is known, that information should be conveyed to the public so the public can knowledgeably engage in community decision-making regarding whether to apply the technology broadly. Public and policymakers need to know the cost of a program applying the technology, the cost and effectiveness of the technology compared with alternatives, and how the money spent on the program might otherwise be used.

Public health institutions also might have an interest in the information purveyed by the companies that market genomic technologies because their advertisements influence the understanding and attitudes of the general public. If public health ethics demands an informed public for informed decisions, public health

institutions may need to counter disinformation or false promises about genomic technologies. (A compendium of dubious genetic promises is available online at <http://www.quackwatch.org/01QuackeryRelatedTopics/Tests/genomics.html>). Moreover, through misinformation, people may purchase unhelpful tests or medications with precious health dollars that would be better spent on other health products or services. In such a way, misinformation affects the health of the public. Preventing misinformation or mandating the presentation of certain information, such as that seen in food and drug labeling, is one of the regulatory functions of public health.¹⁴ Currently, genetic testing does not come under Food and Drug Administration regulation.

7. Public health institutions should act in a timely manner on the information they have within the resources and the mandate given to them by the public.

This principle, which complements principle 5, implies that public health institutions should not idly collect information they cannot act upon, including in situations where there is no prevention or treatment available. It raises questions about banking DNA samples under the belief that the data will become useful in time. These data may represent a resource that is looking for a research question, which can lead in turn to inappropriate uses of the data.

Acting "within the resources and mandate given to them by the public" suggests that decisions to apply genomic technologies are

made in the context of limited resources, competing needs, and public input (principle 3). The argument made under principle 5 (seeking information), that some information may be a low priority and thus should not be sought, suggests that, in some cases, acting in a "timely manner" might mean not acting at all, or at least not using an unproven technology.

We must ask the question: How much information is enough? When is the pursuit of more information an evasion of the responsibility to act on adequate information? This question pertains, of course, not only to genomics but also to the health promotion policies and programs that might compete with genomics for funding.

8. Public health programs and policies should incorporate a variety of approaches that anticipate and respect diverse values, beliefs, and cultures in the community.

This principle, which is mostly about diversity, complements the principle about ensuring access of resources to disenfranchised people. Often, people are disenfranchised because they differ in some way deemed inferior or unacceptable by the dominant culture. Inability to speak the language of the dominant culture (English, in the United States) is a marker for a person who is of another culture and is likely to have some values and beliefs that differ from the mainstream. This may include values and beliefs about the uses of genomic tools or genetic information. When public health institutions rely on or promote the application of genomic tools, they should



anticipate that immigrants from Latin America, for example, might need to have the tool explained to them in ways different from those used with non-Latinos, and perhaps in Spanish. Even then, the institutions may need to accommodate strong cultural sensitivities about the tool.

The number of cultures or other measures of diversity is virtually endless. They cannot all be anticipated or accommodated. Each community needs to discern those that are most important in its own setting.

9. Public health programs and policies should be implemented in a manner that most enhances the physical and social environment.

Juxtaposing genomics with the idea of enhancement begs the question, what is enhancement? Is enhancement, for example, manipulation of genes to make plants more disease resistant and nutrient rich? Or is enhancement avoiding genetic engineering in favor of the natural variation that is part of a complex ecology?

Would the elimination of people with certain characteristics through genetic testing and abortion enhance our social environment by reducing disease and suffering, or would our society suffer because we lose our respect and compassion for people who do not meet a certain standard? Also, because such tests may not be available to all, any benefits or harms will not be randomly or evenly distributed, thereby creating or exacerbating disparities.

10. 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.

The case of the Burlington Northern Railroad and carpal tunnel syndrome, mentioned under principle 2, illustrates how genetic information can be used to discriminate, underscoring the importance of measures to protect the confidentiality of such information. Iceland is an example of a country that has established a populationwide genetic database. It acted in collaboration with a private company named deCode to decipher genetic associations with disease risk and onset to develop new drugs and diagnostic tools.¹⁵ There is potential for misuse of genetic information in settings where effective measures are not taken to protect data confidentiality.¹⁴

In other cases, people may not wish to know their own genetic information. Implicit in the notion of the community good, which is inherent to a public health perspective, is the realization that 1 person's actions affect other people; that is, people are interdependent. With genetics, it is clear that not only do 1 person's actions affect other people, but information people have about themselves is of direct relevance to their parents, siblings, and children.

11. Public health institutions should ensure the professional competence of their employees.

Because of the newness of genomics, few in public health have received any training in the field. The needed skills have been

identified by the Centers for Disease Control and Prevention (<http://www.cdc.gov/genomics/training/competencies/comps.htm>) and the National Coalition for Health Professional Education in Genetics (<http://www.nchpeg.org/nchpeg.html?http://www.nchpeg.org/eduresources/core/core.asp>). As genomic applications become more common in public health, it will be unethical for public health practitioners to be ill informed and unable to inform the public or influence policy.

12. Public health institutions and their employees should engage in collaborations and affiliations in ways that build the public's trust and the institution's effectiveness.

A positive example of collaboration is North Carolina's Genomics Task Force, organized and coordinated by the Office of Genomics within North Carolina's Division of Public Health, with active participation by individuals from government, academia, medicine, industry, non-profit organizations, and the public. The task force produced a genomics plan for the state.¹⁶ This 30-page document contains a proposed strategy for integrating genomic discoveries into the state's public health practices.

In some situations, public health institutions need to act not as collaborators but as regulators. There is a tremendous opportunity for financial gain by companies marketing genomic tools. Public health institutions must be alert to the potential for deceptive marketing approaches that do not enable individuals to

make appropriately informed purchases or decisions. The complement to public-private collaboration is therefore regulation.

CONCLUSIONS AND RECOMMENDATIONS

Some of the genetics-related ethical issues raised by the Public Health Code of Ethics are those commonly identified in discussions based in medical ethics, such as the confidentiality of genomic information. However, the Public Health Code of Ethics also identifies a number of issues that infrequently arise in medically oriented discussions of genomics and ethics. For example, the population orientation of public health leads to questions about allocation of resources for the overall good of the community. Putting resources toward the evaluation of genomic tools may mean fewer resources for other public health services. Moreover, the combination of a population orientation and the value of democratic processes points to the need to inform the public about the strengths, limitations, and costs of genomic tools, as well as processes for communities to voice their opinions on DNA databases and other large-scale genomics projects. Public health's concern for the most vulnerable in society raises questions about the ways in which the application of genomic tools might exacerbate existing disparities.

Genomic tools also raise new questions for public health ethics. While the code mentions prevention and fundamental causes, ge-



nomic tools cause us to refine our thoughts on what fundamental causes are and what constitutes prevention. Also, our growing ability to manipulate genes leads us to consider when genetic modification is enhancement and when it might lead to unintended consequences that outweigh any benefits. It also points to the need to deal with how we define “normal,” “desirable,” and “healthy.”

To refine our thinking in public health ethics and to employ genomic tools ethically, we will need a public health workforce that has skills in both ethics and genomics. The necessary skills have been defined for ethics by the Public Health Leadership Society (<http://www.phls.org>) and for genomics by the Centers for Disease Control and Prevention (cited under principle 11). Research into health policies related to genomics and ethics also will be needed to advance our ability to protect and promote the health of the public in ways that are consistent with the ethical values of the field of public health. ■

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