

Of genomics and public health: Building public “goods”?

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“Global public goods favor the mechanism of public information resources and free and open communication therein. Global public goods once produced should benefit all. Like a clean environment, knowledge about human health has no one institutional home. Like the gene pool at the level of the species being considered the common heritage of humanity, so genomic databases while recognizing the initial contribution of individual participants and of individual researchers or commercial investors should also account for the needs of present and future generations and foster and promote international collaboration.”¹

All signs point to the potential for the Human Genome Project to provide tools for the translation of genomic knowledge to clinical diagnosis, with implications for every level of the health care system.² Indeed, “[g]enomics is inspiring the development of very large longitudinal cohort studies and even studies of entire populations to establish repositories of biological materials (‘biobanks’) for discovery and characterization of genes associated with common diseases.”³ With these “biobanks,” an important advance in human genetics will be the identification and characterization of numerous common genetic variants at specific loci that increase or decrease the risks for various diseases singly and in combination with other genes and with various chemical, physical, infectious, pharmacologic and social factors. Yet, when applied to such population studies and to the ensuing accompanying genomic databases, current consent and privacy mechanisms may limit the use of these biobanks for public health research.^{4,5}

Although the publicly available sequence map of the human genome was preceded by other international collaborative efforts^{6,7} such as the mutation database initiative and, more recently, by the International Haplotype project, these essential scientific building blocks of understanding raise only limited privacy concerns.^{8,9} More problematic are the privacy issues facing population banks that study genotype and phenotype interaction.¹⁰ Currently still under construction, these human genetic research databases will constitute an immense public resource.¹¹

Coupling human genomic databases with databases of pathogens yields the promise of a strengthened scientific basis for the primary and secondary prevention of disease. Combined with understanding of environmental factors, it will eventually provide the basis for programs of health promotion and disease prevention, when public health powers permit.

Norms for the emergence of a new paradigm for public health interventions must be informed by issues beyond the legal and ethical parameters of autonomy and privacy.¹² Indeed, the fundamental reason why contemporary medical ethics has so little to say about public health is that its focus

on individual autonomy suggests that all compulsion for the sake of health is wrong. Yet “many public health measures must be compulsory if they are to be effective.”^{13,14} Thinking at the level of populations or groups requires a vetting of current ethical and legal principles and the development of a concept of the public good or of “common” goods.¹⁵

Privacy directives in Europe, laws in the United States and guidelines in Canada often treat personal genetic information as distinct from medical and personal data.¹ Classical approaches to public health are based on the model of epidemic control, and the rise of autonomy and privacy legislation in the last decades has left little room for ongoing surveillance.¹³ In short, genomic databases are pulled under this “genetic privacy” umbrella even when they are limited to the study of genomic variation (e.g., HapMap [www.hapmap.org], CARTaGENE [www.cartagene.qc.ca]). Such databases can range from descriptions of sequences, to annotated and curated databases, to disease-specific and, finally, longitudinal population databases such as the United Kingdom biobank (www.biobank.ac.uk). While basically oriented toward the building of scientific infrastructures and resources on genomic variation rather than individual disease-oriented studies on specific cohorts, there is no doubt that their potential usefulness for public health surveillance of genomic susceptibility to diseases is immense.

A new paradigm for public health intervention must be informed by issues beyond the legal and ethical parameters of autonomy and privacy.

The concept of public goods has its roots in the 18th century. Hume coined the expression “providing for the ‘common good’” in his *Treatise on Human Nature* (1739). Two main qualities exemplify “pure” public goods: its benefits are nonrivalrous in consumption (i.e., one person or group’s use does not preclude another person or group’s use of a public good) and nonexcludable (i.e., no one can be excluded from benefiting from a public good). Likewise, the “benefits of epidemiological intelligence are nondivisible for all countries.”¹⁵

Ultimately, humanity as a whole should be the beneficiary of global public goods. The qualifying mark of a global public good is that it meets the needs of present generations without jeopardizing those of future generations.¹⁵ It is the latter quality together with those of non-rivalry and non-excludability that led the HUGO (The Human Genome Organization) Ethics Committee in its 2002 Statement on Human Genomic Databases¹⁶ to take the position on primary genomic sequences that:

1. Human genomic databases are global public goods. (a) Knowledge useful to human health belongs to humanity. (b) Human genomic databases are a public resource. (c) All humans should share in and have access to the benefits of databases.¹⁶

Policy development in this area must take contextual and cultural factors into consideration.¹⁷ To avoid untoward effects, genetic research that identifies differential risks in populations requires special consideration before they are incorporated into laws, regulations or public health practices.^{18,19} One of the underlying values of Canada's 2004 proposal for health protection renewal legislation is to "include public engagement in the decision-making process." Both collective and individual rights and interests are at stake in creating or accessing genomic databases for public health research.²⁰ It is also this "population focus [that] distinguishes public health from the clinical enterprise that is governed by the Hippocratic imperative with its focus on the individual patient."⁶ It would be shortsighted indeed to fail to develop ethics for public health genomics, for the public funding of resources such as large genomic databases is ultimately premised on their usefulness in the public interest.

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