

Ethics of public health surveillance: new guidelines



On June 23, 2017, WHO issued the first international ethics guidelines on public health surveillance (appendix),¹ helping to fill a key gap in knowledge regarding this important practice.

Surveillance constitutes the foundation of outbreak and epidemic responses, but it is important not only for infectious disease but also for understanding the global challenge of non-communicable diseases. Surveillance can help to create accountable institutions by providing information about health and its determinants and an evidentiary basis for establishing and evaluating public health policy. Surveillance will be central to the success of the Sustainable Development Goals² proposed by the UN. When the results of surveillance are shared with populations and policymakers in a timely and appropriate manner, they can serve as a tool for advocacy. Perhaps most crucially, surveillance contributes to reducing inequities; the needs of populations in which suffering occurs, particularly when this suffering is unfair, unjust, and preventable, cannot be addressed if these populations are not first made visible.

Yet surveillance has sometimes been the subject of pitched battles. Because surveillance can involve practices such as name-based reporting, it can trigger profound concerns about intrusions on privacy, discrimination, and stigmatisation, particularly in the absence of public trust that names will be secured and not inadvertently disclosed, or that aggregate data will only be released in a sensitive manner.

Just as often, however, the failure to undertake public health surveillance has generated political and ethical controversy because of concerns that “what does not get counted does not count.”

Despite the existence of landmark international guidelines on the ethics of research, including epidemiological studies, and specific ethical guidelines for surveillance of specific diseases in specific countries, there has never been a comprehensive international ethics framework governing public health surveillance that considers risk factors, environmental conditions, infectious diseases, non-communicable diseases, outbreak situations, and national borders.

WHO’s International Guidelines on the Ethics of Public Health Surveillance have been developed by

an international group of experts in surveillance, epidemiological research, bioethics, public health ethics, and human rights. The authors of these guidelines combine expertise in leading research institutions, representing major non-governmental organisations that either undertake surveillance or are involved with surveillance-related advocacy. Among others, experts from the US Centers for Disease Control and Prevention, the European Centre for Disease Prevention and Control, the Chinese Center for Disease Control and Prevention, and WHO provided vital technical support to ensure that the guidelines were reflective of the actual procedures used for and issues involved in data collection, analysis, and dissemination. The Global Network of WHO Collaborating Centres for Bioethics³ initiated this project.

These new guidelines were motivated by a set of core ethical and policy questions, as follows: (1) what is the ethical obligation to undertake public health surveillance; (2) what are the risks of conducting disease surveillance, and how should such risks be balanced against population-level benefits; (3) when and how must relevant communities be engaged in the development of surveillance plans; (4) how should the confidentiality of surveillance data be protected; (5) what are the ethical obligations to share the results of public health surveillance with public health authorities, with public health researchers, and with communities and individuals who have contributed to surveillance systems; (6) are there circumstances when data sharing must be strictly prohibited; and (7) what institutional mechanisms should be established to ensure ethical issues are systematically addressed before data collection, use, and dissemination?

The guidelines are rooted in the tradition of public health ethics, the focus of which has been on articulating and assessing the moral issues that arise in the pursuit of population health. Concepts such as the common good, equity, solidarity, reciprocity, and population wellbeing are, as a result, central to these guidelines. This is not to say that autonomy, privacy, and individual rights and liberties are not also important ethical considerations. However, the social or public values that frame these guidelines illustrate the importance of community and the traditions of good governance. Some use the language of solidarity,

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For WHO International Guidelines development see:
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See Online for appendix

drawing on the communitarian tradition in public health; others, the mutual obligations of reciprocity. The Nuffield Council on Bioethics, for instance, sought to define the duties and responsibilities of government with the concept of stewardship.⁴

The new public health surveillance guidelines describe the affirmative duty to undertake surveillance but also note its limits. Countries have a duty to establish effective surveillance systems. When necessary, such efforts must be assisted by the global community, although such an obligation does not give high-income countries the freedom to ignore the priority-setting decisions of countries that require support. Surveillance can justifiably require that names or other individually identifying features be reported to public health registries to assure the accuracy and utility of surveillance systems. However, countries must also protect reported identifiable data from misuse or abuse. Surveillance serves to support policy making and advocacy, so governments have an obligation to publicise the results of surveillance activities and to act to ameliorate, to the extent feasible, the issues that are revealed by surveillance systems. Finally, it is crucial to create oversight mechanisms to assure that the ethical foundations of surveillance activities are reflected in policy and practice.

These guidelines will be applied to situations that might vary in fundamental ways, and they recognise that value trade-offs are sometimes inevitable. For instance, countries with different local traditions and priorities might strike a different balance between competing values and priorities. It is important to highlight, however, that not all trade-offs are morally acceptable. There may be local, national, or regional circumstances characterised by gross violations of human rights. For example, an occupational disease surveillance system that resulted in routine dismissal of workers affected by silicosis, black lung, or asbestosis would be unacceptable. Trade-offs under such circumstances could provide a pretext for further oppression and should be guarded against.

The WHO Guidelines for Ethics in Public Health Surveillance are offered as the basis for the development

of ethical national surveillance systems. They represent a starting point for the sustained discussions that surveillance demands. But they are, most fundamentally, central to the justification of surveillance as a core activity that extends beyond outbreak contexts or infectious diseases.

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- 1 World Health Organization. WHO guidelines on ethical issues in public health surveillance. June 23, 2017. <http://apps.who.int/iris/bitstream/10665/255721/1/9789241512657-eng.pdf> (accessed June 26, 2017).
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- 4 Hepple B. Public health: ethical issues. London: Nuffield Council on Bioethics, 2007.