



World Health  
Organization

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ISBN 978-92-4-151265-7

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**Cataloguing-in-Publication (CIP) data.** CIP data are available at <http://apps.who.int/iris>.

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# Foreword

Public health surveillance is the bedrock of outbreak and epidemic response, but it reaches far beyond infectious diseases. It is sometimes called the radar of public health: it allows health officials to map disease, spot patterns, identify causes, and target interventions. Surveillance, for example, is central to understanding the increasing global burden of noncommunicable conditions. By helping to determine patterns and causes of morbidity and mortality, it can help guarantee access to safe food, clean water, pure air, and healthy environments.

Surveillance, when conducted ethically, is the foundation for programs to promote human well-being at the population level. It can contribute to reducing inequalities: pockets of suffering that are unfair, unjust and preventable cannot be addressed if they are not first made visible. But surveillance is not without risks for participants and sometimes poses ethical dilemmas. Issues about privacy, autonomy, equity, and the common good need to be considered and balanced, and knowing how to do so can be challenging in practice.

I am pleased to see WHO leading in this important area by placing ethics at the heart of public health surveillance. The *WHO Guidelines on Ethical Issues in Public Health Surveillance* is

the first international framework of its kind, it fills an important gap. The goal of the guideline development project was to help policy-makers and practitioners navigate the ethical issues presented by public health surveillance. This document outlines 17 ethical guidelines that can assist everyone involved in public health surveillance, including officials in government agencies, health workers, NGOs and the private sector. I gratefully acknowledge the many experts and WHO colleagues who have made important contributions to this publication.

WHO has rightly asserted that public health surveillance, conducted in a manner that anticipates ethical challenges and proactively seeks to reduce unnecessary risks, provides the architecture for social well-being. It is now up to the global community and countries to take up this challenge and implement the guidelines in their surveillance systems.



A handwritten signature in black ink, appearing to read "M. Kiely".

Dr Marie-Paule Kiely  
Assistant Director-General  
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# Acknowledgements

This document was prepared by the WHO Global Health Ethics team, led by Andreas Reis and coordinated by Abha Saxena of the Department of Information, Evidence and Research in the cluster of Health Systems and Innovation.

WHO extends special thanks to the co-chairs of the WHO Guidelines Development Group: Amy L. Fairchild, Texas A&M University School of Public Health, USA, and Co-director for the Columbia University WHO Collaborating Centre for Bioethics, and Ali Akbar Haghdoost, Kerman University of Medical Sciences, Islamic Republic of Iran.

Amy Fairchild was lead writer and chief editor. Ali Akbar Haghdoost contributed technical text and was responsible for ensuring the accuracy of the document with regard to the operation of surveillance systems. Angus Dawson and Lisa Lee contributed substantially to formulating the guiding principles and discussions. Calvin Ho Wai Loon provided core text on legal systems and issues. Jennifer Gibson contributed text on accountability and governance. Ronald Bayer, who was Chair of the Network of Collaborating Centres for most of the duration of this project, played a pivotal editorial role, with Ross Upshur and Carla Saenz. Ronald Bayer, Michael Selgelid, and Angus Dawson substantively addressed comments from the Guideline Development Group and external reviewers. Michael Selgelid, Andreas Reis, Amy Fairchild and Ronald Bayer prepared grant proposals to fund the work.

WHO gratefully acknowledges the contribution of the WHO Guidelines Development Group, which shared extensive knowledge, original text and comments on the document. All are also co-authors of the document:

Kokou Agoudavi, Ministry of Health, Togo; Jimoh Amzat, Usmanu Danfodiyo University, Nigeria; Ronald Bayer, Columbia University Mailman School of Public Health, USA; Philippe Calain, Médecins Sans Frontières, Switzerland; Yali Cong, Peking University Health Science Centre, China; Angus Dawson, University of Sydney, Australia; Claire Gayrel, University of Namur, Belgium; Jennifer L. Gibson, Joint Centre for Bioethics, University of Toronto, Canada; Kenneth Goodman, University of Miami, USA; Vijayaprasad Gopichandran, Tamil Nadu School of Public Health, India; Einar Heldal, Institute of Public Health, Norway; Calvin Ho Wai Loon, National University of Singapore Centre for Biomedical Ethics, Singapore; Hussain Jafri, Council for Alzheimer's, Pakistan; Lisa M. Lee, Presidential Commission for the Study of Bioethical Issues, USA; Sergio Litewka, University of Miami, USA; Mina Mobasher, Kerman University of Medical Sciences, Islamic Republic of Iran; Keymanthri Moodley, Stellenbosch University, South Africa; Boateng Okyere, University of Ghana, Ghana; Maria Consoria Quizon, Training programs in Epidemiology and Public Health Interventions Network, Philippines; Pathom Sawanpanyalert, Food and Drug Administration, Thailand;

---

Michael Selgelid, Monash University, Australia; Ross Upshur, University of Toronto, Canada; Effy Vayena, University of Zurich, Switzerland.

The Global Network of WHO Collaborating Centres for Bioethics and their members are gratefully acknowledged.

WHO thanks the support provided by various observers: Ehsan S Gooshki, Tehran University, Islamic Republic of Iran; Katherine Littler, Wellcome Trust, United Kingdom; Debra Mosure, Centers for Disease Control and Prevention, USA; Patricia Sweeney, Centers for Disease Control and Prevention, USA; and Hans van Delden, Utrecht University Medical Centre, Netherlands.

The support and contributions of two consultants is greatly appreciated: Carl H. Coleman, Seton Hall Law School, USA, and Michele Loi, Swiss Federal Institute of Technology, Switzerland.

This guidance document benefited from the work of a literature review group, comprising: Corinna Klingler, Ludwig Maximilian University Munich, Germany (lead); Diego S. Silva, Simon Fraser University, Canada; Daniel Strech and Christopher Schürmann, Hannover Medical School, Germany; and Michael Vaughn, Columbia University School of Public Health, USA.

WHO's Global Health Ethics team extends thanks to the WHO internal steering group for its invaluable advice on development of the guidelines: Isabel Bergeri, Marie-Charlotte Bouesseau, Somnath Chatterji, Joan Helen Dzenowagis, Sergey Romualdovich Eremin, Jesus Maria Garcia Calleja, Margaret Orunya Lamunu, Anais Legand, Ahmed Mandil, Tim Nguyen, Bruce Jay Plotkin, Manju Rani, Leanne Margaret Riley, Pascal Ringwald, Carla Saenz Bresciani, Nahoko Shindo, and Matteo Zignol,

as well as WHO colleagues Ronald Johnson, Vasee Moorthy, Mahnaz Vahedi, Amin Vakili, and Jihane Tawilah.

The document also benefited from the work of an external review group, comprising: Larry Gostin, Georgetown Law Center, USA; Philip Zucs, Gaetan Guyodo, Marieke van der Werf, European Centre for Disease Prevention and Control, Sweden; Nijuan Xiang, Public Health Emergency Centre, Centers for Disease Control, China; Martyn Kirk, College of Medicine, Biology and Environment, Australian National University, Australia; Thilaka Chinnaya, Ministry of Health, Malaysia; Mohammed Ben Ammar, formerly at the Ministry of Health, Tunisia; Lorna Luco, Universidad del Desarollo, Institute of Bioethics, Chile; and Preet Dhillon and Shifalika Goenka, Public Health Foundation, India.

Special thanks are extended to former interns of the Global Health Ethics team who contributed to this document: Nicholas Aagaard, Sara Birch Ares, Hannah Coakley, Christine Fisher, Antonia Fitzek, Theresa Fuchs, Sandrine Gehriger, Christina Heinicke, Sophie Hermann, Katalin Hetzelt, Felicitas Holzer, Patrik Hummel, Helene Maree Jacmon, Euzebiusz Jamrozik, Selena Knight, Pat McConville, Sarah McNeill, Jan Nieke, Julia Pemberton, Maansi Shahid, Alexander Shivarev, and Michael Vaughn.

WHO gratefully acknowledges Phuong Bach Huynh, School of Public Health, Texas A&M University, for the design of the cover page.

Preparation of this guidance document would not have been possible without the generous support of the Fondation Brocher, Switzerland; Monash-Warwick Alliance Seed Fund Scheme project on "Ethics of Public Health Security", Australia; Wellcome Trust, United Kingdom; and the Institute for Bioethics and Health Policy, University of Miami, USA.



The WHO Strategic Health Operations Centre (SHOC) May 3, 2009.

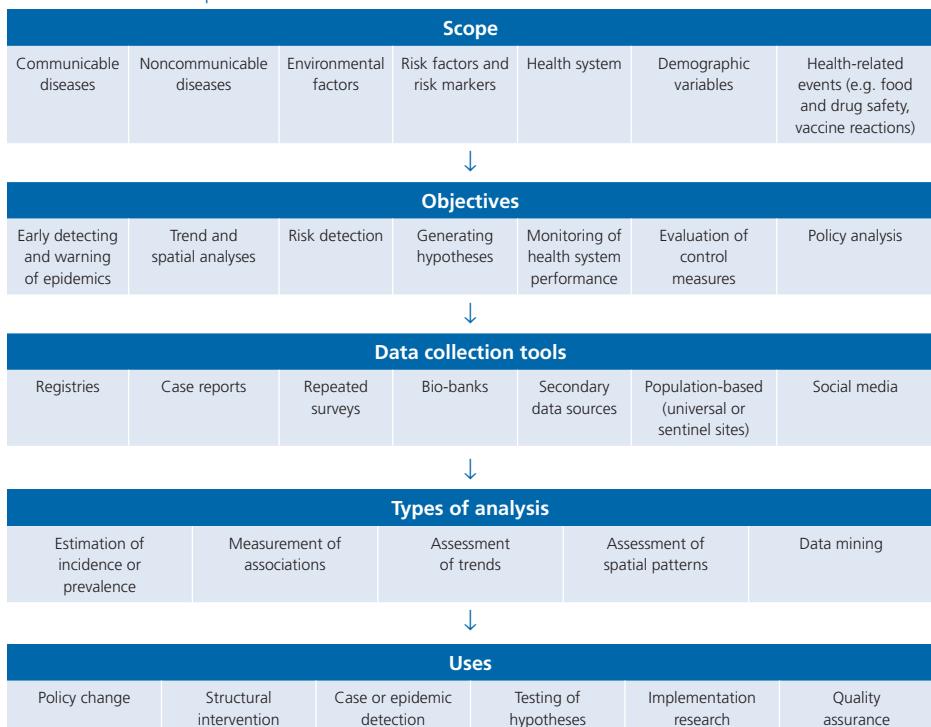
Source: WHO /Christopher Black

## I. Introduction

Disease surveillance has been a basic public health activity since the late nineteenth century (see Table 1). It is the foundation for initiatives to promote human well-being at the population level. Public health surveillance is the bedrock of outbreak and epidemic response, but it reaches far beyond infectious diseases. It can contribute to reducing inequalities: pockets of suffering that are unfair, unjust, and preventable cannot be addressed if they are not first made visible (1). It is central to understanding the increasing global burden of noncommunicable conditions. By helping to determine patterns and causes of morbidity and mortality, public health surveillance can help guarantee

access to safe food, clean water, pure air, and healthy environments. Continuous environmental surveillance may not only identify concerns but also trigger alerts. Occupational disease surveillance can identify workplace exposures and lead to regulation. Surveillance can help create accountable institutions by providing information about health and its determinants. It can provide an evidentiary basis for establishing and evaluating public health policy. Surveillance, for example, will be central to the achievement of the United Nation's Sustainable Development Goals. The availability of the results of surveillance enables and promotes policy choice. Thus, access to surveillance information can serve as a tool for advocacy when the results are

Table 1. Dimensions of public health surveillance



Source: A.A. Haghdoost

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shared with populations and policy-makers in a timely, appropriate manner.

Yet surveillance has been the subject of sometimes bitter controversy. Public health surveillance may limit not only privacy but also other civil liberties. For example, surveillance may trigger mandatory quarantine, isolation, or seizure of property during an epidemic (2). When surveillance involves name-based reporting (that is, reporting by name), it can, to the extent that populations are made aware, trigger profound concern about intrusions on privacy, discrimination, and stigmatization. Name-based reporting can also seriously harm people and property, as is seen when mob reactions supersede care, compassion and the effective rule of law. Concern is compounded in the absence of trust that the public health system will keep names secure or will release aggregated data and related information (referred to simply as “data” from this point forward, as records contain information that varies in type and scope) in a sensitive manner (2). In some countries, the HIV/AIDS pandemic sparked controversy about tracking by name those carrying the virus, but, even when confidentiality was assured, when details of risky behaviour and affected populations became public, groups like gay sex workers and injecting drug users experienced social harm such as discrimination and stigmatization. Because of these concerns, the HIV/AIDS epidemic spurred ethical and regulatory guidelines at both national and international levels that could be used in planning, collecting and then using personal and aggregated data.

Just as often, however, *failure* to conduct public health surveillance has generated political and ethical controversy because of concern that “what doesn’t get counted doesn’t count”. Environmental and occupational health advocates, for example, have long made this argument. Even for events deemed critically

important, yawning gaps in surveillance remain. The 2014–2016 Ebola virus disease crisis dramatically underscored the potentially devastating consequences of a lack of capacity to monitor the incidence and spread of disease. An effective public health or clinical response can be seriously hampered by the absence of such data. But if Ebola virus disease is a high-profile example of the costs of inadequate systems and the importance of support from the global community for vital surveillance, many other occupational and environmental exposures – like asthma, silicosis and conditions related to exposure to arsenic or lead – go uncounted in both high- and low-income countries. Some commentators have argued that, too often, only when a public health crisis becomes a “threat to international peace and security” does surveillance become a priority for wealthy countries (3). But even when surveillance is a priority, fragmented, unlinked or consolidated data sets remain a problem for their effective use for public health purposes.

While surveillance is often conducted without public knowledge or concern when the risk for stigma, discrimination or perpetuation of inequity is high, surveillance inevitably involves conflicts of values and judgements about how to advance public health goals without harming individuals or groups in society. Thus, the priorities and the distribution of resources for surveillance merit public debate, not only within societies but among global communities. Despite landmark international guidelines on the ethics of research, including epidemiological studies, and specific ethical guidelines for surveillance of particular diseases and/or in particular countries, there has been no international ethics framework to guide public health surveillance systems in general that spans infectious diseases, noncommunicable diseases (NCDs), disease outbreaks, environmental and occupational exposures, and even national borders. The Council for International

Organizations of Medical Sciences (CIOMS), the World Medical Association and others have identified this gap (4). It is crucial to have ethical guidance as a baseline for judging public health surveillance for all diseases and exposure across national borders.

The fragmented, disease-specific nature of international guidance is not surprising, given the uneven, incomplete state of public health surveillance in both high- and low-resource settings and different national and subnational mandates for surveillance in different legal systems. It is imperative to address the ethics of public health surveillance in a way that cuts across conventional boundaries, for a number of reasons.

Public health operates in an era of global health threats, such as AIDS, severe acute respiratory syndrome (SARS), influenza, Ebola virus disease, Zika virus infection, obesity and coronary heart disease. Given the zoonotic origin of many of the conditions, surveillance will increasingly involve monitoring the animal-human interface. For example, surveillance of food and animal feed for pathogens must be linked to surveillance for the same pathogens in humans.

Surveillance is conducted in a context in which there have been significant advances in the capacity to collect and share data from previously unimagined sources, such as social media or geospatial mobile phone data. There have been parallel technological leaps in possibilities for identifying disease; genetic analysis, as just one example, allows rapid identification of pathogens or pathogenic strains. At the same time, inequalities within societies and within the global community have become more marked. There are growing gulfs in the capacity of different nations and locales to take advantage of technological change. Civil conflicts in different countries inevitably trigger health crises



Dog and pig vendor at market day, Atsabe, Ermera.

Source: WHO / SEARO /Joao Soares Gusmao

that draw the attention of both United Nations agencies and humanitarian organizations. Crisis situations, in turn, deepen inequalities and create additional barriers to surveillance and intervention in conflict zones (3).

This remarkable epidemiological, social, economic, political and technological global landscape makes it imperative to fill the gap in international guidelines and to address the ethics of public health surveillance explicitly. That is the aim of these international guidelines on the ethics of public health surveillance. They were prepared by an international group of experts in surveillance, epidemiological research, bioethics, public health ethics and human rights. The authors of these guidelines represent leading research institutions and also nongovernmental organizations (NGOs) either involved in surveillance or representing groups and populations with a vital interest in both the benefits and burdens of surveillance. The authors also represent countries in both the south and north, with different political systems, social values and priorities.

The guidelines were prepared in collaboration with the global network of WHO Collaborating

Centres for Bioethics, which initiated the project. They also drew on the technical support of the US Centers for Disease Control and Prevention to ensure that the guidelines took account of the actual procedures for and cost of data collection, analysis and dissemination and can thus reasonably be used. The guidelines are based on a systematic literature review of relevant research and grey literature in accordance with the WHO Handbook for Guideline Development (5).

The goal of the guideline development project was to identify key ethical considerations to guide resolution of controversies that may arise in surveillance, which itself is an ethical obligation of governments. Specific ethical issues are addressed in contexts that differ in terms of culture, values, resources, political traditions and institutional structures, with sometimes very different expectations for the importance of individual rights, community solidarity and/or the good of society. The guidelines also address challenges that arise in contexts characterized by persistent injustice and/or repeated violation of human rights. These guidelines cannot therefore provide concrete answers to all the difficult questions raised by

public health surveillance. Rather, on the basis of a set of core considerations for the ethics of public health, the guidelines establish the duty to conduct surveillance, share data and engage communities transparently, while recognizing the limits of that mandate. The 17 guidelines should not be read in isolation from each other or from the discussion of each of them. They jointly lay out the issues that those involved in surveillance (including officials in government agencies, health workers involved in surveillance, NGOs and the private sector) should consider and weigh carefully when making decisions about the collection, analysis, sharing, communication and use of surveillance data.

While the guidelines do not specify a mechanism for oversight, the conclusion is that, in view of the overarching imperative to conduct surveillance, analyse the data and act on the results, responsibility and accountability must ultimately be based on a sustainable, practical mechanism for ensuring that the ethical challenges posed by public health surveillance are anticipated and addressed systematically and transparently. Countries should ensure implementation of these guidelines and monitor it regularly.

## II. Background

### Defining public health surveillance

Some countries define surveillance narrowly, others quite broadly. These guidelines cover surveillance as broadly understood. In the simplest formulations, surveillance is defined as “continued watchfulness” (6) or “the monitoring of events in humans, linked to action” (7). WHO generally defines surveillance as “the continuous, systematic collection, analysis and interpretation of health-related data needed for the planning, implementation, and evaluation of public health practice” (8). Health data are those pertaining to communicable and NCDs, injuries and conditions and their related risks and determinants. For infectious disease outbreaks (and events that suggest a “potential for international disease spread”), the International Health Regulations (2005) (IHR) define surveillance as “the systematic on-going collection, collation and analysis of data for public health purposes and the timely dissemination of public health information for assessment and public health response as necessary” (9).

Understanding of public health surveillance differs considerably from country to country. Although surveillance is usually described as systematic or continuous, not all countries, institutions or scholars single out the routine nature of public health surveillance but rather emphasize the purpose and function of data collection (see Table 1). Likewise, although disease and injury always figure centrally, some definitions include determinants of important public health events (10) and environmental conditions that affect health (11). Vital registration of events like births and deaths, although often not specifically described as part of a “public health” surveillance system, is often considered to be surveillance.



Health worker collecting records and filling out surveys with the inhabitants of Salto, Uruguay.

Source: WHO/TDR /Sebastian Oliel

Although international agencies often sponsor, subsidize and oversee national surveys in low- and middle-income countries to track trends in risk factors or health outcomes, national public health authorities are usually responsible for public health surveillance systems and activities. The IHR, however, recognizes surveillance data from beyond the formal channels of reporting, including unofficial or informal sources, provided that they meet standards of reliability and validity.

For some organizations and experts, only those activities in which the purpose of data gathering has been defined in advance and, indeed, in which the questions driving data collection are set in advance meet the definition of public health surveillance (12). The Australian Department of Health uses a broader epidemiological definition of surveillance: the continuing scrutiny of all aspects of the occurrence and spread of disease that are pertinent to effective control (13). Some designations explicitly exclude case-finding (and subsequent testing and treatment), public health investigations and epidemiological research (12), while others consider that “use of epidemiological



**Bedside computer in the diabetic ward of the King's Hospital, London, 1970s.**

Source: WHO /Peter Larsen

information” falls within the scope of surveillance (14). A surveillance system may thus cover not only infectious diseases and involve not only continuous data collection but may also include focused epidemiological studies; inspection of hazardous conditions or broad oversight of the potential danger posed by food, water or the environment; and screening at workplaces or in health establishments. Table 1 gives an overview of the activities that fall within public health surveillance.

While there may be broader and narrower definitions, the understanding of surveillance is that data are collected with the intent of enabling public health action, whether direct intervention, priority-setting, resource allocation or advocacy. “Knowing about the health of a community,” noted one group of surveillance specialists, “is the first step to making improvements that support healthy behaviours, identify and address unusual health events, and prevent and treat disease and injury.” (12) In addition to linking surveillance to action to achieve some goal, almost all countries, institutions and experts underscore the importance of communicating surveillance results to those “who need to know”, including the public, policy-makers, national and international scientific communities, programme planners, public health authorities, medical institutions and funding agencies, to enable intervention, sustainable development or advocacy.

The landscape of public health practice is also changing rapidly with regard to the kind of data to which public health agencies have routine access. In some settings, data are recorded by hand and stored on paper; in others, they are collected, stored and shared via sophisticated electronic systems. The era of “big data,” as discussed in section V, may hold enormous potential for the future of public health surveillance, broadly understood, and has already raised vexing ethical questions.

In some jurisdictions, surveillance systems could soon be linked directly to electronic health records. Interoperability between public health surveillance data sources and clinical practice is within reach, in both the public and the private health care sectors (15). Public health data can be used to inform automatic decision-support systems or computational tools to trigger alerts and warnings. Research has shown, further, that geospatial mobile phone data could accurately describe and predict the movement of individuals and thereby the spread of diseases like malaria and H1N1 influenza (16-18).

These guidelines define public health surveillance systems broadly, building on the general WHO definition of continuous, systematic collection, analysis, interpretation, and sharing of health-related data for advocacy and for planning, implementing, and evaluating public health practices. Even if systems are operative, however, new, focused studies are required to respond to epidemiological threats. Further, public health surveillance systems not only rely on but may also inform and improve clinical practice.

## Surveillance: ethics, law and history

Nation states have established surveillance systems that differ in scope and purpose. International law and regulation have been important means of ensuring at least a basic level of public health surveillance in all countries. In 1969, the WHO Member States adopted the IHR, a revision and consolidation of the International Sanitary Regulations, as the framework for strengthening health security in an increasingly interconnected world. They came into force in 1971 (19). The IHR impose a legal obligation on all Member States to have certain core public health capacities, including surveillance and data collection, with the goal

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of preventing, controlling or responding to the international spread of disease.

Experience with the SARS crisis of 2003 led the World Health Assembly to adopt a significant revision of the IHR on 23 May 2005 (9). While the IHR had originally focused on a short, fixed list of communicable diseases, the revised regulations – IHR (2005) – allow flexibility to target any disease that may constitute a public health emergency of international concern. They also establish an obligation to create core capacity for surveillance and outbreak response to disease and “public health events”. As of November 2014, however, 48 countries had failed to communicate their capacity or plans, and another 81 had asked for extensions to coming into compliance (20). The recent outbreak of Ebola virus disease revealed that many countries had not satisfied their obligations under the IHR; only 64 countries – one third of those bound by the IHR – “had achieved these core capacities”. Nevertheless, while all countries are required to comply with the IHR, limited resources and political instability can pose obstacles to surveillance, and it may not be possible to overcome these obstacles without international assistance.

The IHR (2005) are limited in the sense that they provide mainly a framework for governance in addressing “public health emergencies of international concern”. The framework is neither for constructing comprehensive surveillance systems nor for grappling with the ethical issues posed by surveillance systems and practices. International regulation, like national law and regulation, is an important tool that establishes a duty to conduct surveillance while also setting limits on that practice. What is legal, however, is not always ethical. Ethics is an essential tool for critically evaluating law, regulation and practice and for addressing the value conflicts that may be posed by surveillance.

Local and national surveillance systems emerged in the nineteenth century, and almost all comprised physicians’ case reports. The data were initially used almost exclusively to document either social progress or misery (21). At the heart of the most bitter battles over individual rights and population health, however, were surveillance measures that made intervention at the level of individuals possible, with the discovery of germs and the realization that many diseases were spread from person to person. Interventions based on communicable disease reports were sometimes welcomed (leading to referral to clinics, provision of food and clothing) but were sometimes a cause of alarm (when leading to mandatory vaccination or treatment, quarantine or deportation). Official morbidity reports were usually protected against public disclosure by law, regulation, and practice. Surveillance was also the basis for population health measures, such as the pasteurization of milk, regulation of food and drug manufacture, housing reform and other measures that addressed the structural causes of disease. Resistance to such measures, largely on the part of independent and incorporated businesses, was often framed as an issue of individual rights.

Physicians, worried about interference with their patients and use of their time, often resented, resisted or simply ignored mandates for reporting. But not all monitoring of morbidity and mortality required identification of cases by name. Reporting of sexually transmitted diseases, for example, was often done by code instead of name in industrialized countries (21). Contact tracing, of course, required names, but most physicians kept the index case anonymous when patients cooperated by providing the names of sex partners and adhering to treatment. Whether names were necessary or whether informed consent was required often framed debates as surveillance was extended, over

the course of the twentieth century, to NCDs such as cancer, diabetes and stroke and to occupational exposures, substance use, road accidents, injuries, vaccination status and vaccine reactions (22).

During the twentieth century, it was often people affected by a disease or condition who challenged the need for surveillance; but, just as often, the story of surveillance has been one in which affected groups have demanded the “right to be counted” (22). NCD surveillance, in contrast to infectious disease surveillance, has been underfunded and “woefully inadequate,” even in high-income countries (23). Workers exposed to toxic hazards and citizens vulnerable to environmental pollutants have sometimes joined social movements as a means of gaining both attention and the resources necessary for surveillance; however, the more common story is that chronic disease threats, particularly those of vulnerable populations, remain invisible.

Global crises often expose systemic challenges that are insufficiently addressed. Undocumented migrants with tuberculosis are still not included in statistics submitted to WHO by some countries (24, 25), but it would be a mistake to assume that the only challenges are the absence of surveillance or under-reporting. Tuberculosis surveillance data, for instance, were critical for determining levels of funding from the Global Fund to Fight AIDS, Tuberculosis and Malaria. Surveillance staff sometimes



Industrial pollution. Moscow, Russia.

Source: WHO /Sergey Volkov

found themselves under high pressure to reach what some criticized as unrealistic targets. They had to choose between showing “good” results or losing their jobs, adversely affecting the quality of data in some settings (26, 27).

These guidelines are based on the understanding that surveillance is so fundamental a public health practice that its advancement cannot depend on crises or citizen protests to make the case for tracking disease for the sake of public health. While these guidelines represent a call to action, it is not a call to unrestrained action. Rather, public health surveillance, conducted in a manner that anticipates ethical challenges and proactively seeks to reduce unnecessary risks, provides the architecture for social well-being.

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### III. Framing the ethics of surveillance

#### Existing guidelines

Limited academic literature on the practice of public health surveillance addresses the major ethical questions that arise in data collection; when the data are actually stored, used and shared; and data dissemination. The academic literature is (28), however, no substitute for guidelines that go beyond current disease-specific, national recommendations (29).

In the decades since the Second World War, both international and national bodies have proposed ethical principles, guidelines and laws to govern research with human subjects. In response to egregious harm inflicted on individuals coerced into clinical research, new codes of ethics uniformly prioritized individual self-determination and emphasized the importance of informed consent for research, while acknowledging that it would hardly be straightforward in complex situations to balance the protection of human research subjects against the social benefit of the research. In the practice of clinical ethics, autonomy assumed a place of singular importance, representing a fundamental change in a moral world view (30-33).

In its “International guidelines for ethical review of epidemiological studies” in 1991, CIOMS acknowledged that existing guidance focused on “patients and individual subjects” was not sufficient for studies involving “groups” of people. After considerable controversy, a consensus emerged: CIOMS stressed the importance of the principles of research ethics first set out in the Nuremberg Code but recognized that application in the epidemiological context would require flexibility (34). The tradition that developed was one in which research

ethics committees could waive a requirement for informed consent when the risk posed by epidemiological research was “no more than minimal” and obtaining consent would make the research “impracticable” (34).

While public health surveillance may share methodological strategies with epidemiological research, it is not simply another form of research. In surveillance a community is the subject of concern. That surveillance is one of the responsibilities of public health was recognized in 1991 by CIOMS, which described surveillance in emergency outbreak situations as clearly requiring exemption from ethical review and oversight. In dire situations, surveillance could not “await the formal approval of an ethical review committee” (34). Emergencies, however, accounted for only a small part of surveillance activities.

Not until its 2009 revision did CIOMS guidelines explicitly support continuous case-based public health surveillance (in the absence of informed consent). The revision stated, “Several considerations support the common practice of requiring that all practitioners submit relevant data [to public health surveillance registries]: the importance of having comprehensive information … about an entire population, the scientific need to include all cases in order to avoid undetectable selection bias and the general ethical principle that burdens and benefits should be distributed across the population.” (35) This position echoed that of the Nuffield Council on Bioethics in the United Kingdom. In 2007, the Council warned against allowing individuals to opt out of reporting, arguing, “We are aware of several examples [in which] consent requirements have or could have had serious negative consequences.” (36) Despite this sweeping endorsement of mandatory nominative case reporting without consent, the Council underscored the inevitability of

making ethical judgements about the limits of surveillance (36).

Neither CIOMS nor the Nuffield Council provided more guidelines on ethics for public health surveillance, nor did they resolve the vexing problem of how to distinguish surveillance from research on human subjects. Are there morally relevant differences between public health surveillance and research (4, 37)? Do they require different general guidelines and oversight mechanisms? Does, indeed, public health surveillance require *any* kind of formal guidelines or continuous oversight? Drawing the line between research and surveillance – or between research and other forms of vital social inquiry such as quality improvement, implementation research, oral history or even journalism – has been challenging, but definitional solutions have (to date) proved inadequate (38, 39). Accordingly, a leading group of surveillance experts underscored the need “to move past the formal demarcation between research and

practice” (29). These guidelines seek to do so, not by laying out new definitions but by setting into bold relief both the centrality of public health surveillance to population well-being and the need for appropriate ethical guidance and review – that is, for a paradigm of accountability that responds to the demands of public health and that is distinct from the systems that have governed research for half a century.

## Public health ethics

The discipline of public health ethics has developed rapidly during the past two decades. Its central focus has been on articulating and exploring the ethical issues that arise in the pursuit of population health. This has resulted in a focus on concepts such as the common good, equity, solidarity, reciprocity, and population well-being. This is not to say that more individual values such as autonomy, privacy, and individual rights



A crowd at a community event to launch a vaccination campaign.

Source: WHO /Garry Smyth

and liberties are not also important ethical considerations; however, these more “social” or “public” values are reflected in related yet not wholly overlapping concepts that capture the broad importance of community and the affirmative duty to act. Some in the field use the language of solidarity (40), drawing on the communitarian tradition in public health (41); others describe the mutual obligations of reciprocity (42). The Nuffield Council on Bioethics sought to capture the duties and responsibilities of government in relation to public health by the concept of “stewardship” (36).

After a careful review, reflection and deliberation, the WHO Guidelines Development Group determined that the following ethical considerations are of particular importance for public health surveillance. They represent the backbone of the guidelines:

**Common good:** Surveillance is widely acknowledged to be a public good (43), and some of the benefits it provides cannot be subdivided into individual private benefits because they are fundamentally shared (41, 44). Surveillance is justified, fundamentally, as a requirement for the good of all. Without adequate oversight by public health bodies and the participation of individuals and communities, the shared benefits of surveillance are at risk. There is a complex literature on economics and moral philosophy that seeks to define and distinguish the terms “public good”, “public goods,” and “the common good” (45). After careful deliberation, the committee adopted the term “the common good” to capture the notion of public goods more broadly conceived than in the narrow economic sense.

**Equity:** Public health ethics is centrally concerned with the idea of equity. It is well established that social inequality has adverse effects on health (46). Not all inequality is within human control or is morally relevant. Morally problematic inequality is commonly referred to as inequity. A just or fair society will attempt to provide equitable conditions for humans to flourish, with health as a central component. Equity sometimes requires that the most vulnerable people receive what may appear to be disproportionate resources: that is, the unfair distribution of risks requires additional resources to balance the scales. Public health surveillance can further the pursuit of equity by identifying the particular problems of disadvantaged populations, including global communities, providing the evidence for focused health campaigns and identifying the basis of unfair differences in health.

**Respect for persons:** Public health ethics is concerned with the rights, liberty, and other interests of individuals as well as overall population well-being. Whenever possible, individuals should be involved in decisions that affect them. In some cases, individuals should be free to make their own choices; in other cases, when population-level interventions may be necessary, individuals can be consulted and involved in decision-making. But many individuals (such as young children) cannot make their own choices, and the State has an obligation to protect them and promote their long-term health interests. Undertaking public health surveillance is, itself, arguably an expression of respect for persons. This further requires ensuring that data about individuals and groups are protected and risks for harm are minimized

to the greatest possible extent. Finally, surveillance further engenders respect for persons by making protection or amelioration possible.

**Good governance:** Although good governance is not an ethical principle but rather a political aspiration, it is subject to a number of ethical considerations. To ensure that the ethical challenges posed by public health action are addressed systematically and fairly, governance mechanisms must be accountable and open to public scrutiny. Although protection of the common good must draw on the best available evidence, decisions will have to be made in the face of uncertainty. Accountability, transparency and community engagement are means of justifying public policy structures that promote respect for persons, equity, and the common good. Transparency requires that policies and procedures for surveillance be communicated clearly and that affected individuals or communities be aware of any decisions concerning them. Transparency also requires public reporting of the results of surveillance (in anonymized or aggregated form). Without such knowledge, communities cannot be empowered to demand government action or to protect themselves in the absence of alternatives.

These are not the only relevant ethical considerations with regard to the nature of surveillance programmes and practice but the ones considered central to making decisions in the specific context of public health surveillance by those involved in development of these guidelines.

While over the past few decades the global discourse on research ethics has come to

an agreement on how best to frame issues, public health ethics has not reached such a juncture. Thus, even in documents explicitly grounded in public health ethics, differences in language and emphasis remain. This document is one of three recent WHO-sponsored initiatives to develop ethical frameworks for disease control. Building on the original "Guidance on ethics of tuberculosis prevention, care and control" in 2010 (47), the "Ethics guidance for the implementation of the End TB Strategy" (48) addresses the most critical challenges to reducing the number of deaths from tuberculosis by 95% by 2030 and the number of new cases by 90% between 2015 and 2035. The "Guidance for managing ethical issues in infectious disease outbreaks" (49) in 2016, in response to the outbreak of Ebola virus disease in West Africa in 2014–2015, underscored the importance of providing ethics guidance beyond "a specific pathogen in isolation" to "cross-cutting ethical issues that apply to infectious disease outbreaks generally".

The three projects obviously have important continuity. All, for example, emphasize equity, justice, and the common good (sometimes expressed as "stewardship" or "reciprocity"). All stress the importance of respecting the dignity of persons (sometimes emphasizing autonomy or privacy). Accountability and the importance of good governance either explicitly or implicitly informs all three. They also have relevant differences that reflect the subject of each. The tuberculosis guidelines, for example, address the problem of drug-resistant disease and thus emphasize the harm principle. The guidelines on infectious disease outbreaks, framed as they were by concern for groups in conditions of tremendous vulnerability and the ways in which outbreaks can become crises, further amplified by fear and distrust, places greater emphasis on human rights. Given the need to make decisions in

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the face of uncertainty, they also stress utility, proportionality and efficacy.

The ethical considerations outlined above and repeated and amplified in the guidelines that follow are, in the estimation of this committee, central to justification of surveillance as a core activity, beyond outbreaks or infectious disease situations. They must be applied in situations that may vary in fundamental ways. The guidelines recognize that trade-offs of values are sometimes inevitable. The local traditions and priorities in countries may sometimes result in a different balance between competing values and priorities. It is important to stress, however, that not all trade-offs are morally acceptable. Local, national, or regional circumstances may be characterized by gross injustice or violations of human rights. In these contexts, rather than serving the common good, public health surveillance may be used as an instrument for violation of respect for persons, equity, and justice. In countries where sex work is a criminal offense, for example, HIV surveillance can be used for oppression.

Likewise, an occupational disease surveillance system that results in routine dismissal of workers affected by silicosis, black lung, or asbestosis would be unacceptable. Appeal to “trade-offs” under such circumstances could well be a pretext for further oppression and should be guarded against.

The State is a source of both intrusion and protection. Some disease burdens and forms of health oppression simply cannot be made visible without State-sponsored surveillance (50). On the one hand, surveillance makes public health interventions to address inequities possible. On the other hand, surveillance may be used to impose additional burdens on those who are already disadvantaged. The only assurance that surveillance will amount to neither privilege nor punishment is attention to the ethical considerations described above: both burdens and benefits should be critically weighed and then fairly distributed in a transparent manner in which States are held accountable.

## IV. Guidelines

As a consequence of the development of ethical norms for the conduct of research during the past few decades, research ethics committees have been established in almost all countries. As surveillance does not fall under the rubric of research, however, there has been no systematic framework for continuous ethical oversight or analysis of the challenges posed by surveillance activities. The following guidelines are premised on the conclusion that ethical scrutiny of public health surveillance is necessary.

The guidelines are, necessarily, not prescriptive; rather, they seek to highlight trade-offs that must be carefully and routinely weighed. They do not provide concrete definitions, measures, precise surveillance parameters or oversight mechanisms that might, on the surface, appear to make decision-making less complex. Concepts like “legitimate public health purpose”, “disproportionate burden”,

“community engagement” and “good governance” cannot be regarded as universal yardsticks for use by decision-makers. Rather, agreement on definitions for use in different contexts lies at the very heart of the vexing political and ethical judgements that must be made: grappling with the meaning of concepts in specific local and national settings represents a first step in ethical engagement.

The following guidelines, then, cover (i) the broad responsibility to undertake surveillance and subject it to ethical scrutiny; (ii) the obligation to ensure appropriate protection and rights; and (iii) considerations in making decisions about how to communicate and share surveillance data. These guidelines represent a starting point for the searching, sustained discussions that public health surveillance demands. Like other international guidelines on research ethics, the ethics of surveillance will require continuous review and revision in the light of experience.



Kim Pai factory, Bangkok, June 2015.

Source: WHO /Diego Rodriguez

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## **Guideline 1. Countries have an obligation to develop appropriate, feasible, sustainable public health surveillance systems.**

**Surveillance systems should have a clear purpose and a plan for data collection, analysis, use and dissemination based on relevant public health priorities.**

Member States have an ethical duty to protect population health – not only that of their citizens but that of all people within their borders, including refugees, undocumented workers, and individuals in transit (51) – and to address the disparities that characterize the distribution of morbidity and mortality. The duty to protect population health is the foundation of an affirmative responsibility to conduct public health surveillance. The exercise of that responsibility may be assigned to subnational governmental bodies.

Without public health surveillance systems, population health cannot be protected and inequalities cannot be adequately addressed. Inattention to pressing public health needs leads to erosion of trust. Thus, from the perspective of the common good, the *failure* of countries and the international community to undertake adequate public health surveillance represents a central moral concern. The importance of population health thus imposes upon States an obligation to develop systems that capture data critical to identifying and responding to (outbreaks of) infectious diseases, epidemic threats and the toll exacted by injuries and chronic disease, which demand environmental and occupational monitoring or investigation. A commitment to equity and justice can uncover the ways in which patterns of morbidity and mortality reflect and contribute to social inequality. As such comprehensive systems are beyond the capacity of some countries, the international community, as described in Guideline 6, has the obligation to provide support.

Passive systems of surveillance are often sufficient, such as monitoring seasonal outbreaks of influenza from incidence and prevalence rates that include neither names nor case verification with costly laboratory tests for all individuals with influenza-like syndromes. Even in the instance of influenza, however, systematic community-based surveillance provides a more accurate depiction of outbreaks. The State might have to establish active surveillance systems, taking proactive steps, for example, to find data: this might require examining clinical records to ensure complete reporting and to confirm an influenza diagnosis. Cancer registries in some countries have included such active surveillance.

Surveillance systems often entail the enactment of regulations and statutes that impose upon clinicians, health care administrators or laboratories a duty to report to public health registries. To ensure effective surveillance of disease priorities, it is often necessary to mandate the reporting of individually identifiable data, including names and other socio-demographic characteristics. Such intrusion on clinical confidentiality is justified when names are required to ensure the collection of accurate data, which is separate from the need to target interventions. But accurate data and targeted interventions both rest on the moral obligation to prevent harm to others and the common good or to provide the best resources to populations according to the burden of disease, as in the case of cancer registries. Guidelines 11 and 12 outline the ethical limits to name-based reporting.

Public health surveillance activities require investment of societal resources to preserve, protect and promote health. In all countries, but especially in low-resource settings, allocating societal resources for public health surveillance requires prioritization. This issue is discussed further in Guideline 5.

Once surveillance data are available, Member States have the moral duty to use the data actively to promote better health outcomes. Even when resources limit the capacity of countries to take immediate action on the basis of the findings of public health surveillance, the data provide the evidentiary basis for advocacy directed at both the national

and global communities, thus potentially empowering the most vulnerable. The pursuit of equity establishes a warrant for surveillance, and the global community should provide the necessary help in moving from collecting and analysing data to action (see Guideline 6).



The school nurse is the most efficient link between the school and the home.

Interior view: a nurse is examining two young children in the dining area of the home; the mother is standing to the left; further to the left is a large stove situated next to a fireplace.

Source: The National Library of Medicine

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## **Guideline 2. Countries have an obligation to develop appropriate, effective mechanisms to ensure ethical surveillance.**

Public health surveillance has inherent benefits for the functioning of the public health system, as well as risks. Countries should have an appropriate, effective mechanism for ensuring adherence to ethical standards in both emergency and non-emergency situations. Decisions about changing an established surveillance system can pose important ethical challenges. Examples of changes that may require ethical scrutiny include: collecting data elements that reveal stigmatized behaviour; adding new elements of data collection, such as measurements of CD4 counts as part of routine HIV/AIDS surveillance; adopting new uses for existing surveillance data, such as for case management or contact tracing; or using public health surveillance data for commercial or security purposes.

In the case of research, review committees monitor adherence to ethics standards. Such an independent, impartial oversight mechanism allows for close scrutiny and can ensure that relevant protection is in place. These guidelines do not recommend mechanisms that mirror those that have emerged in the context of research ethics. However, public health surveillance is currently not subject to routine oversight. It is the obligation of countries to decide the most appropriate processes for identifying and addressing the ethical issues that arise in public health surveillance.

Box 1 provides some examples of existing mechanisms. Any mechanism or process should ensure ethical implementation of surveillance without itself becoming an obstacle to achieving the larger public health goal. (We address the nexus of surveillance and research in Guideline 16.)

Such mechanisms of ethical oversight should effectively identify the risks and benefits of surveillance and suggest measures to enhance the benefits, minimize the risks and ensure appropriate weighing of the common good, equity, and respect for persons. Oversight should be continuous, and any substantial changes proposed to the surveillance system should be evaluated through an “ethical lens”.

Ethical monitoring of surveillance can be facilitated and enhanced by training public health personnel. Such training can emphasize the importance of integrating ethical analysis early and explicitly when developing and implementing a surveillance system.

While the establishment of an independent, impartial ethics oversight mechanism is warranted, concrete implementation will depend on the social, political, legal, and cultural context in which surveillance is conducted (52). Research usually entails discrete projects with time-limited horizons, whereas surveillance usually involves continuous monitoring as opposed to a one-time review. The most appropriate mechanism for ethical scrutiny should be chosen in a transparent, accountable fashion. (See guidelines 2 and 5 and the discussion of good governance in section III.)

## **Box 1. Examples of oversight mechanisms**

### ***Public Health Ontario (Canada)***

In 2012, Public Health Ontario published “A framework for the conduct of public health initiatives”. It applies an integrated approach for ethics review, in which all evidence-generating initiatives undergo ethical scrutiny proportionate to the level of risk. Its Ethics Review Board plays a vital role in helping to ensure that research and other initiatives conducted by Public Health Ontario are carried out in a manner that is consistent with the second edition of the Federal “Tri-council policy statement on ethical conduct for research involving humans and other relevant regulations, policies and guidelines”. The Ethics Review Board addresses research, evaluation, surveillance, and quality improvement projects that involve human participants, their data, or their biological materials. Membership of the Board complies with the provisions of the Federal policy statement with regard to expert representation and composition, with members selected from Public Health Ontario and public health units and academic institutions in Ontario. They have expertise in various public health disciplines and in methodology, law, and ethics; the members also include community representatives. (Source: <https://www.publichealthontario.ca/en/About/Pages/Ethics-Review-Board.aspx>)

### ***Centers for Disease Control and Prevention, Public Health Ethics Unit (USA)***

The Centers for Disease Control and Prevention established the Public Health Ethics Unit in the office of the Associate Director for Science, which collaborates with the Public Health Ethics Committee. It provides support throughout the institution; its aims are to “integrate the tools of ethical analysis into day-to-day operations”. It provides training, fosters and sustains a culture of ethical analysis, and provides guidance for and support in ethics consultations. (Source: <https://www.cdc.gov/od/science/integrity/phethics/>)

### ***National Health Service clinical governance committee (United Kingdom)***

The National Health Service in the United Kingdom distinguishes between research and non-research activities. Individuals involved in audits, programme evaluation, or public health surveillance are directed to seek advice from the clinical governance office of their local National Health Service organization. (Source: <http://www.nhs24.com/aboutus/nhs24board/boardmeetingsandcommittees/clinicalgovernancecommittee/>)

### ***Public Health Ethics Consultation Service, WHO***

The Global Health Ethics Unit at WHO created a new mechanism in 2015 to help colleagues working in public health to address ethical issues. Like those of the Ethics Review Board of Public Health Ontario and the Public Health Unit at the Centers for Disease Control and Prevention, the mandate of the Public Health Ethics Consultation Service extends beyond surveillance. Programmes and initiatives are not required to be reviewed by this service: WHO staff solicit advice as needed in order to maximize flexibility and ensure that ethical consultation is not viewed as a bureaucratic hurdle. Its advice is informal and non-binding. The group is made up of WHO staff, who receive continuing training in public health ethics and seek advice from the global network of WHO Collaborating Centres for Bioethics. (Source: <http://www.who.int/ethics/en/>)

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### **Guideline 3. Surveillance data should be collected only for a legitimate public health purpose.**

Governments and others involved in public health surveillance should collect only information that is relevant for legitimate public health purposes, such as to protect, enable or enhance public well-being, reduce morbidity and mortality, increase access to the health system and services and reduce health disparities and thereby inequities. All further discussions of public health surveillance in these guidelines is based on the assumption that it is undertaken exclusively for a legitimate public health purpose.

Literature on good governance usually considers legitimate measures to be those that are publicly defensible, morally justified and/

or socially acceptable in pursuit of a common good. (53, 54) Any collection of personally identifiable information that does not meet these conditions would be ethically problematic. A legitimate public health purpose is required not only for the collection of data but also for the further use of data already in hand.

Data collected for clinical purposes (for example to diagnose infectious disease, to monitor microbial resistance, to monitor NCDs like diabetes or to track behaviour associated with coronary heart disease or obesity) can be used for legitimate public health surveillance purposes, provided that such use meets the criteria bar set in guidelines 1, 3, 4 and 7–14 of this document. Such repurposing requires adequate protection of data security and confidentiality (Guideline 10).



**Children's Environmental Health in India.**

Source: WHO /Diego Rodriguez

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#### **Guideline 4. Countries have an obligation to ensure that the data collected are of sufficient quality, including being timely, reliable and valid, to achieve public health goals.**

Data should meet the most exacting yet reasonable standards with regard to completeness, uniqueness, timeliness, validity, accuracy and consistency for the purpose and the resources available to fulfil that purpose. Where relevant, this requirement extends to external quality assurance of laboratory data. The quality of data is a precondition of their ethical use. Determining the adequacy of data, however, depends, in part, on whether they are to be used to intervene at the level of the individual (e.g. contact tracing) or the population (e.g. estimating the incidence and prevalence of a disease or exposure). Their adequacy will also depend on whether a disease is infectious, noncommunicable or environmental, and whether the condition is chronic or acute. How data quality is assured from a technical perspective will depend on the priority, the context and the type of surveillance. While some countries and institutions explicitly stress the accuracy or reliability of data (55), others value rapid collection of useful data over complete accuracy.

Countries have obligations to ensure sufficient numbers of trained staff to generate and competently analyse surveillance data

and promote quality. The quality of surveillance data can be improved not only by formal technical evaluation but also by regular audit and benchmarking against national and international norms (56). Countries have an obligation to educate people who contribute to surveillance about its goals and to explain why surveillance is conducted, what risks might arise, how those risks can be minimized and any appropriate legal and ethical obligations. Individual health care workers, professional bodies, and agencies (like hospitals and laboratories), in turn, have a professional obligation to support and contribute to maintaining the integrity of surveillance activities and to ensure that data of the best possible quality are obtained.

Counterintuitively, data quality may be compromised by widely used performance-based funding mechanisms. Too great an emphasis on achieving targets, linked to funding, can undermine the integrity of surveillance. For example, countries may be pressured to produce data to secure resources, and staff may have to choose between providing either the data desired by funders or the correct data and risk losing their jobs. Realistic target-setting at international and national levels and broader international support for surveillance (Guideline 6) are possible solutions to counteract the scramble for funding that produces unreliable data.

## **Guideline 5. Planning for public health surveillance should be guided by transparent governmental priority-setting.**

Public health surveillance involves the investment of resources that could be allocated to meet other goals, such as clinical care or prevention (57). Furthermore, within the resources available for public health surveillance, priorities must be set. Given competing goods, the allocation of scarce resources must inevitably engage questions of equity and efficiency. As no absolute standard can guide such determinations, it is critical that decision-making be transparent, fair and open to revision (58). Governments are accountable for how priorities are set. Transparency is important because it fosters trust and creates conditions for citizens to advance the common good individually and collectively (59).

Transparency is essential with respect to: (i) the aims and duration of any public health surveillance activity, (ii) the rationale for such activity relative to explicit health or health care system goals, (iii) the intended benefits and potential burdens to citizens and other actors of public

health surveillance, (iv) the scope and methods to be used in collecting data, (v) the intended uses of data and by whom, (vi) the mechanism by which use of data will be monitored, (vii) the mechanism by which subsequent use of data would be overseen at community level and (viii) the recourse that citizens or other actors may have if public health surveillance fails to meet legal and/or ethical standards. Surveillance data should be publicly reported (see Guideline 13) to the extent that they will increase public trust, serve the aim of promoting and protecting public health nationally and internationally and will not unduly harm any identifiable group or exacerbate inequity (54, 58).

Citizens should have access to mechanisms to express their concerns and priorities with regard to surveillance. For example, communities may express concern about a potential cluster of birth defects or cancers that necessitates not only targeted epidemiological studies but also the creation of surveillance systems. Priorities should not be set solely by experts nor by those with access to health officials and policy-makers, neglecting populations with less opportunity to voice their concerns.



Pandemic containment exercise (simulation), conducted by the Ministry of Indonesia with the support of WHO Indonesia.

Source: WHO / SEARO /Nursila Dewi

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## Guideline 6. The global community has an obligation to support countries that lack adequate resources to undertake surveillance.

Some countries may be unable to establish and maintain public health surveillance of sufficient quality, even for high-priority targets that could greatly reduce health inequalities and improve population health, because of severe resource constraints. Equity provides the ethical foundations for claims to international support. The global community – international health organizations, NGOs, major foundations, countries with a global leadership role – has an ethical responsibility to work collaboratively with these countries to support public health surveillance and subsequent interventions. The aim of this requirement of global justice is to reduce health inequalities among countries and improve global health.

For example, preventing and limiting the global spread of disease was a key rationale for the obligations under the IHR. Given that outbreaks and risk factors do not recognize borders, the global community also has an interest in having sustainable surveillance systems, even in countries that do not have the means to establish and maintain them (20). Likewise, effectively addressing NCDs and environmental threats requires international support for surveillance (60, 61). Agencies with a strong capacity for surveillance should regularly update technical guidelines for best practices. The international community should help to ensure that both technical and ethical training is widely available.

Surveillance may require support not only for technical capacity, however, but also for systematic, formal ethical evaluation and improvement, as demonstrated by global support for training in research ethics. Thus, international organizations also have an

obligation to facilitate and encourage countries to practise good governance by meeting their ethical and legal responsibilities. When countries fail to protect the fundamental rights or interests of individuals or populations in public health surveillance, international support should be contingent on their rectifying such violations and wrongdoings.

An obligation to support does not give the global community license to ignore the priorities of countries that require support or resources. International humanitarian organizations have expressed deep concern that surveillance is too often driven by the security needs of high-income countries, creating ambiguities about who the chief beneficiaries of surveillance are (3). When a country's decisions have been made in a participatory, transparent manner, the global community has an obligation to meet local surveillance aspirations that exceed or even conflict with the priorities set by international donors (62). For example, malnutrition may be a priority for surveillance in a country with limited resources, whereas international donors may view that concern as of lower priority than an infectious disease outbreak. Genuine partnerships may require reform of global health governance, shifting the priority from securitization, politics, and trade to "universal health values" (63).

Too often, data are collected locally but analysed at State or country level, with minimal feedback. Both the international community and country officials should encourage the analysis and use of surveillance data collected at the local level *by* the local level. Local analysis and use can enhance accountability and the capacity to improve population health. When local analysis is not possible, analyses performed at central or national level should be shared with the local level.

## **Guideline 7. The values and concerns of communities should be taken into account in planning, implementing and using data from surveillance.**

Officials, agencies, and organizations responsible for surveillance should try to engage the population beforehand about the goals, processes, and potential impacts (both positive and negative) of surveillance activities as a means of demonstrating respect for persons. When this is not possible or is not done, those responsible for surveillance must bear in mind that their work is being done without consideration of the concerns of the community; those responsible for surveillance necessarily become stewards not only of the common good but of community interests. Engagement is particularly important when a surveillance activity disproportionately burdens a specific population (e.g. through stigmatization). Engaging with communities, especially those that have been historically marginalized, and empowering them to participate actively is particularly important. Given that some public health surveillance activities require coordination at local, national and international levels and involve multiple actors, active inclusion and participation of communities may be useful in building or sustaining trust

across levels and implementing activities more efficiently and effectively.

It is often difficult to define a community, because geographical area is not the only salient characteristic. Shared traditions and values and a common identity may be important defining factors. Health conditions may also help define a community.

The appropriateness of engagement is another subject of debate. Some advocates incorporate community engagement in the design, implementation, monitoring and evaluation of surveillance. Community engagement in the dissemination of results is warranted, particularly when the findings may result in stigmatization or discrimination. For others, a commitment to engagement may be more flexible. Taking account of community values and concerns requires, at a minimum, that legitimate authorities undertake public health surveillance in a transparent manner in accordance with the principles of good governance. Active engagement of the community may involve meetings with community leaders, focus group discussions and other forums that provide an opportunity for members to clearly express their values and concerns (see Guideline 5 and the discussion of good governance in section III).

### **Box 2. Community engagement**

A particularly compelling, flexible method for engaging communities is democratic deliberation. This is a structured method for decision-making that brings together diverse stakeholders to construct solutions to complex policy questions. Participants engage in discussion and dialogue, communicate their perspectives respectfully, and provide justification for their views in a way that everyone involved can grasp. The goal is to make pressing decisions while considering empirical evidence, communities' lived experience, and values. The US Bioethics Commission (64) has used the deliberative method as it has grappled with difficult issues fraught with tension and has made available a variety of training tools (65). While it is only one means of ensuring citizen involvement and is not appropriate for all situations, it has been a staple not only of local and national but also global decision-making. For example, in June 2016, (66) some 10 000 citizens in 76 countries expressed concern about climate change and recommended legally binding measures, including "reporting of [each nation's] adaptation and mitigation efforts" to keep global warming below 2 °C. (67)

## **Guideline 8. Those responsible for surveillance should identify, evaluate, minimize and disclose risks for harm before surveillance is conducted. Monitoring for harm should be continuous, and, when any is identified, appropriate action should be taken to mitigate it.**

Even when public health surveillance is clearly justified to promote the common good, Member States and those responsible for conducting surveillance should remain alert to the possibility that harm can be caused to both individuals and communities (Table 2).

This does not mean that surveillance should not be conducted. Rather, those conducting surveillance have an obligation to identify potential harm beforehand, to monitor for harm during and after surveillance and to put in place processes to mitigate harm. Without continuous monitoring, mitigation is impossible. This is vital, not only because it is wrong to cause unnecessary harm, but also because harm – to both individuals and communities, such as loss of property value or tourism dollars – may also damage public trust in the programme and in public health in general. (See guidelines 5, 12 and 13 and the discussion of good governance in section III.)

In some instances, countries have provided compensation for the harm that might

inevitably accompany surveillance. In the context of SARS, Chinese Taipei gave people who were quarantined the equivalent of US\$ 147 (68). Basic welfare benefits or sick pay for those deprived of work as a result of surveillance are other possibilities. The possibility of compensation should not, however, pose a barrier to surveillance (69).

There are many different types of harm: economic, legal, psychological, social (and reputational) and physical. All should be considered in relation to surveillance (70-72). For example, a migrant or a person in another disadvantaged group may be identified as being at higher risk for an infectious disease through surveillance, and this could lead to stigmatization of the group. Relevant information must be handled very carefully: reputations can quickly be damaged, with devastating results across a spectrum that may include not-yet-documented types of harm (73). Various moral values and ethical principles should be weighed and balanced against each other and a judgement made about fair distribution of burdens and benefits in different surveillance initiatives or systems in a transparent way (see discussions of equity and good governance in section III).

When, despite all efforts to mitigate harm, surveillance entails a predictable risk for harm (stigmatization, discrimination, expulsion or violence), additional precautions should be

**Table 2. Types of harm potentially related to disclosure of public health surveillance data**

Type of harm	Result
<b>Physical</b>	Public attacks, spouse/partner abuse, domestic violence, delayed or inadequate treatment
<b>Legal</b>	Arrest, prosecution, death penalty, expulsion
<b>Social</b>	Discrimination, community discrimination, isolation, inability to access care or exclusion from care, rejection from the community
<b>Economic</b>	Loss of employment or revenue, loss of health care services, loss of insurance, increased insurance premiums, increased health care costs, limited career options, loss of life resources, forced relocation
<b>Psychological/emotional</b>	Distress, trauma, stigma



Health brigades in Chiapas, Mexico, during the epidemic of H1N1 influenza, 2009.

Source: WHO /Harold Ruiz

taken to protect the individuals or communities at risk. The risk for serious harm may, in rare circumstances, be so great that surveillance might be difficult to justify morally. In most cases, however, mitigation strategies can ensure that risks for harm are dealt with adequately. Once harm or potential harm is identified, action must be taken to reduce the risk, or a plan must be in place for reducing, removing or compensating for any harm.

As not all harm can be eliminated, the benefits of surveillance should be proportional to the risk for harm. Protective measures should include the way in which health authorities present information or action to the

media and the broader public. Sensationalist representations of statistical facts can, for example, result in reputational damage and extend the period of economic recovery for those affected by a health issue, as in the case of countries or communities identified as a source of an infectious outbreak. Processes and measures should be in place to mitigate some of the financial and other harmful consequences of surveillance in order to minimize any negative consequences for a community and to maintain trust. Additionally, given their mission to mitigate harm, politically neutral international humanitarian organizations must not be hindered in situations such as civil conflict zones, where international agencies are constrained when it comes to recognizing “opposition parties as operational partners” (3).

Notably, public health professionals themselves sometimes require protection. As champions of the common good, they must be free to report without fear of reprisal. As surveillance officials have a responsibility to speak up, they should have protection. This idea is established in the IHR, which protects the confidentiality of those who report a verifiable outbreak or a public health event outside official channels.

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## **Guideline 9. Surveillance of individuals or groups who are particularly susceptible to disease, harm or injustice is critical and demands careful scrutiny to avoid the imposition of unnecessary additional burdens.**

Individuals or groups in situations of heightened vulnerability bear an undue proportion of health problems. Responsible authorities should make special efforts to ensure that these populations are included in surveillance in ways that will empower them. How exactly situations of vulnerability should be defined is a subject of dispute in the literature (74). Vulnerability may be diffuse, affecting large communities with limited economic development, limited access to health care facilities, educational deprivation, occupational risks or wider disadvantages in society. Public health surveillance and health information systems can provide valuable information to aid the development of health programmes and services to address their health problems and the underlying determinants of health, such as clean water, food security, or gender equality. To promote equity, surveillance should focus on the specific problems of these vulnerable communities.

People with particular susceptibility to disease, harm or injustice are also at increased risk for further burdens, such as discrimination and stigma, attributable to surveillance activities or findings. For example, refugee groups and undocumented migrants with a higher disease burden may be seen, wrongly, as the cause of disease outbreaks. Similarly, workers with an occupational disease, such as silicosis, who lack access to adequate legal support may

be dismissed from work rather than receiving treatment or compensation. Wherever possible, susceptible groups should be identified before surveillance activities begin in order to minimize the risk for harm. In surveillance programmes, there should be constant monitoring for (further) harm to those in conditions of particular vulnerability. When harm does occur, a mitigation strategy should be put in place (see Guideline 8).



The HIV oral test on a brothel bed in Belém do Pará, Brazil.

Source: Laura Murray

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## Guideline 10. Governments and others who hold surveillance data must ensure that identifiable data are appropriately secured.

Responsible data collection and sharing practices should ensure the security of the data collected in order to respect persons and safeguard the privacy and other interests of the individuals and communities concerned (50). Every effort must be made to secure records to prevent unauthorized disclosure. Security is different from privacy and confidentiality, yet it is an essential component of each. "Security" in this context consists of operational and technological safeguards to protect personal data from unauthorized access or disclosure. Maintaining information security is not fool-proof, as electronic databases can be infiltrated.

Governments and others who hold surveillance data must take appropriate technical and organizational steps to protect data

against accidental or unauthorized access, destruction, loss, use or disclosure, whether the data are collected and stored in paper or electronic (digital) format. All personnel with access to public health surveillance data should be trained annually in data security procedures and made aware of their professional ethical responsibility to protect the data and the public. The level of security must be appropriate to the risks and the nature of the data to be protected, taking into account the state of the art and the cost. In particular, sensitive information, which raises the risks of individuals and communities for stigmatization or discrimination, should be subject to specific and especially rigorous security safeguards.

The imperative to secure data should not be considered a license to refuse to use or share surveillance information effectively for legitimate public health purposes. (See guidelines 14–17 on sharing and the discussion in Guideline 2 on meaningful ethics training.)



Staff at the Medical Records Office sort through patient files at Karapitayam Hospital, Galle.

Source: WHO / SEARO /Gary Hampton

## Guideline 11. Under certain circumstances, the collection of names or identifiable data is justified.

In some instances, the collection of names or identifiable data is both technically and ethically imperative. Effective surveillance may require the de-duplication of records (that is, avoidance of double-counting, which can lead to overestimates of incidence or prevalence).

<b>THE NEW CASES REPORTED.</b>	
<b>Names and Addresses of Those Stricken with Paralysis.</b>	
The following is a list of the names and addresses of the new cases of infantile paralysis and deaths in the city yesterday:	
<b>NEW CASES—BOROUGH OF MANHATTAN.</b>	
Morris Katz, 208 E. 7th St. Bella Cohen, 647 E. 11th St. Charles Barisch, 502 E. 16th St. David Shapiro, 241 E. 25th St. Rose Sciascia, 228 Chrystie St. Muriel Weiss, 308 Broome St. Caroline Villini, 218 Bowery. Giuseppe LaRocca, 119 Elizabeth St. Nathan Holneck, 33 Henry St. Stephen Millanovsky, 58 Monroe St. Jenny Serrelese, 359 W. 53d St. William Soles, 458 W. 168th St. Carl Thornhillin, 731 Tenth Av. Bennie Katz, 57-59 E. 112th St. Madeline Schuman, 158 Elizbth Av. Nicoletta Volini, 414 E. 120th St.	
<b>DEATHS—BOROUGH OF MANHATTAN.</b>	
David Shapiro, 241 E. 26th St. Carmelo Cirincini, 246 E. Houston St. Giuseppe LaRocca, 119 Elizabeth St. Bennie Katz, 57-59 E. 112th St. Sam Greenberg, 208 E. 6th St. Bella Cohen, 647 E. 11th St.	
<b>NEW CASES—BOROUGH OF BRONX.</b>	
John Jonnholic, 658 Hewitt Place. Jacob Goldberg, 702 E. 161st St. Harriett Campbell, 462 E. 162d St. Joseph Blum, 342 St. Ann's Av.	
<b>DEATHS—BOROUGH OF THE BRONX.</b>	
John Hamilton, 303 W. 169th St. Died at Riverside Hospital. Theima Arms, 430 E. 141st St. Died at Lincoln Hospital.	

Names and addresses of people with dread diseases were regularly reported in newspapers until the 1960s.

Source: New York Times, July 22, 1916. Public Domain.

Names and other unique identifiers (social security numbers, identity card numbers) may also be essential for longitudinal surveillance registers, which require correct linkage of records on the same individual and/or their relatives or contacts over time. Unique identifiers may likewise be required to link data from different sources (for example, registries of tuberculosis and HIV, or birth defects and Zika virus infection). Critically, names and other specific identifiers are required for outbreak investigation or case follow-up and contact tracing (e.g. to identify and offer testing and treatment to the sexual and needle-sharing partners of people with sexually transmitted infections).

There has been disagreement over whether unique identifiers can be used instead of names. Unique identifiers are expensive to create and, if constructed in a fashion that allows accurate data linkage, could easily be linked back to names. Some countries experimented with coded reporting for HIV infection before ultimately adopting nominative systems. While such systems were initially the only politically viable solution, they were abandoned when they were found not to meet federal funding standards for reliability and validity. However, technological advances have created new possibilities. Digital data can be scrambled and encrypted into unique identifiers that are perhaps impossible to trace back to individuals. Good governance requires that the trade-offs of using names as opposed to unique identifiers or encryption be the subject of continuing, transparent, public discussion that takes into account surveillance system requirements, changing technical capacity, risks, and evolving norms with regard to unique identifiers (which may become ubiquitous) and their legitimate use (75).

Another important consideration in the collection of data is the geographical location of

individuals, which can be an indirect identifier. It is ethically important to prioritize confidentiality during the collection of geolocation data and also for the release or sharing of global positioning system data, which should be geo-masked to minimize risk of disclosure, preserving spatial distribution but preventing identification of cluster-exact geo-coordinates (76).

When the collection of names or unique identifiers is considered imperative, this requirement should be made explicit in planning the programme. Not only will countries make different judgements, but the requirement for names may not be uniform within countries. Personal data may be required only at local level, while anonymized or aggregate data may be sufficient at higher levels in a country or globally.



Drone in clear sky. Robert Lynch.

Source: CC0 Public Domain

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**Guideline 12. Individuals have an obligation to contribute to surveillance when reliable, valid, complete data sets are required and relevant protection is in place. Under these circumstances, informed consent is not ethically required.**

There is a long history of objection to public health surveillance without informed consent. Nevertheless, informed consent is not the default in public health surveillance. Many countries have enacted laws that require such systems to collect personal data without consent, subject to legislatively prescribed safeguards.

All individuals in a population are likely to benefit from surveillance programmes. Individuals, therefore, have a reciprocal obligation to contribute to surveillance and thereby promote the common good. Even when the potential benefit to any one individual is small, as the epidemiologist Geoffrey Rose famously pointed out, the benefit to the community as a whole may be large (77). Population benefits provide the moral obligation for individuals to contribute. If it is possible to opt out (and too many people do so),

public health might be unacceptably compromised (78). Seeking informed consent is often not feasible in practice, e.g. from large populations. It may be prohibitively costly and unwarranted when the risks are low (as in some epidemiological research in which CIOMS has allowed waiving of consent). In some cases, however, consent is the norm, such as in routine descriptive health surveys. It is the obligation of the public health authorities accountable for surveillance to assess the importance and feasibility of seeking informed consent. It is important to clarify that, when consent is required, it must be genuinely voluntary.

Whether or not consent is sought, information about the nature and purpose of surveillance and about any risk for harm should be publicly accessible (see Guideline 13). Relevant protection and adequate governance mechanisms (Guideline 2 and the discussion on good governance in section III), appropriate ethics training (guidelines 2 and 6) and data security (Guideline 10) will enhance trust in surveillance systems and ensure protection.

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### **Guideline 13. Results of surveillance must be effectively communicated to relevant target audiences.**

There is compelling, widely accepted moral justification for dissemination of the results of surveillance to relevant target audiences, although it is not a substitute for ameliorative action on the part of those responsible for surveillance. At the local level, relevant target audiences include the community, community officials and opinion leaders, health care providers (doctors, nurses, health care workers), policy-makers, health advocates and health volunteers. The relevant target audiences may also include Member States, national and international agencies, and NGOs.

Although CIOMS guidelines are focused on research, they stress the importance of communicating results, both positive and negative, to “promote and enhance public discussion”. Without dissemination, the social value of the work cannot be realized. In the absence of appropriate dissemination, those who collect data, including surveillance data, might rightly be accused of exploiting the individuals and groups whose health data they collect and analyse in the name of the common good. The Nuffield Council on Bioethics argued that, for dissemination to be considered appropriate, those from whom data are collected should understand the implications of the results for both health care and prevention (35).

Surveillance findings should be communicated concisely in a way that is understandable to a lay audience and sensitive to community concerns (see Guideline 7). Communication should not seed panic but alert people to relevant risks in a sensible manner. Mass mailings, toll-free information hotlines, social media, newspapers, seminars, and public meetings are all possible means for conveying

surveillance information to the communities from which data were collected and analysed and to the public. In resource-limited settings, street theatre, and folk art and other community-based methods can be adopted for the same purpose. Communication should also provide meaningful information for physicians, hospital managers and other relevant target audiences.

The communication of knowledge is a double-edged sword: on the one hand, knowledge may clearly empower; on the other, it may lead to injury, stigmatization or discrimination. A decision not to broadly publish data might be justified in exceptional circumstances, when doing so might cause significant harm. Likewise, if the affected population is so small (for example, cases of very rare cancers) that identification of individuals, however inadvertent, might be inevitable, communication can be limited to preserve privacy (79).

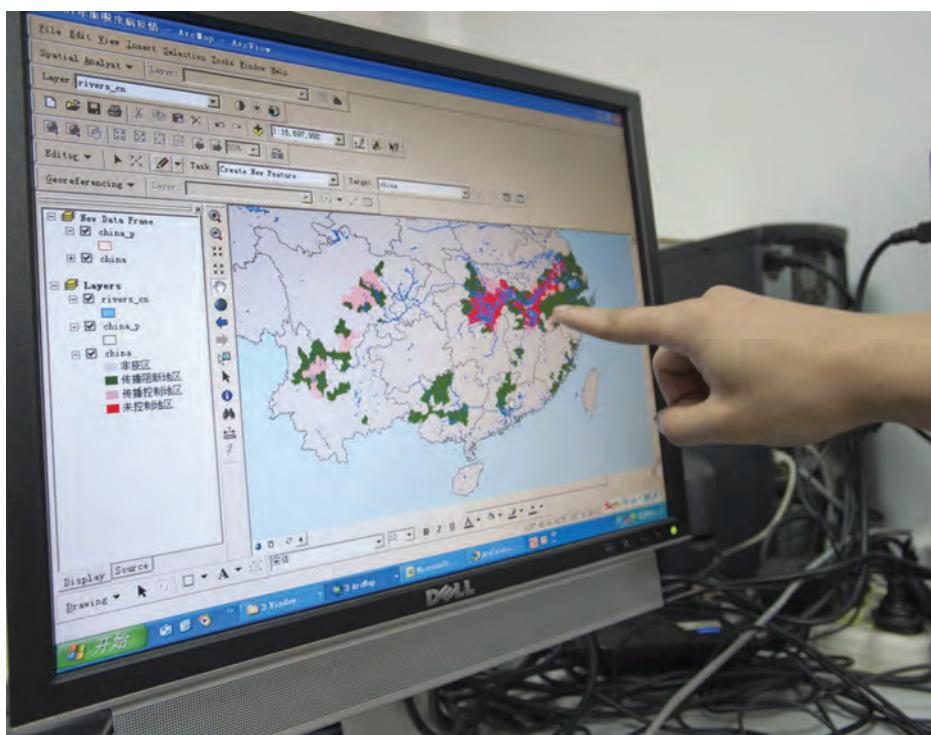
Decision-makers must also weigh the harm that could result if affected communities are not informed and thus deprived of knowledge and the ability to take action to reduce the risks and the capacity to engage in advocacy (see Guideline 13). Those responsible for public health have an affirmative duty to mitigate the burdens that communication might impose on individuals or groups that are more susceptible to harm or injustice.

There is continuing debate about when, if ever, those responsible for the design and conduct of surveillance are ethically obliged to inform the subjects of surveillance about individual results or diagnosis and then refer them to the appropriate service (80). For example, in the early days of the HIV epidemic, when treatment was not available, blinded seroprevalence studies were considered ethically acceptable. In these population-based surveys, HIV status was

not communicated to the study participants. With advances in HIV diagnosis and management, however, the ethical consensus shifted (81). Guidelines now recommend that surveillance systems report results back to consenting individuals (80, 82, 83). Guidelines also recommend that, after returning results to individuals, those with positive results be referred for proper clinical evaluation, treatment and follow-up at nearby health facilities. The guidelines also encourage partner testing (76) and referral for psychosocial

support. This example underscores the importance of surveillance systems having an engaged oversight body to deal with such issues and make changes on the basis of new evidence or emerging best practices in other jurisdictions (Guideline 2).

Relevant ethical considerations in making a judgement about returning information to individuals include feasibility, the possibility of taking action and the potential benefit to the individual.



Map of parasitic disease epidemic area in China at the National Institute of Parasitic Diseases in Shanghai, China. 16 May 2010.

Source: WHO / TDR /Simon Lim

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**Guideline 14. With appropriate safeguards and justification, those responsible for public health surveillance have an obligation to share data with other national and international public health agencies.**

For a public health surveillance system to be effective, equitable, and promote the common good, it must be capable of receiving and linking data from public agencies responsible for public health. For example, because of the stringent data security that has surrounded HIV surveillance, there have been situations in which data on HIV status have not been shared with those responsible for tuberculosis surveillance, obviating systematic identification of cases with co-infection. Public health workers cannot respond appropriately to swiftly changing infectious diseases in real time or take appropriate action in the case of chronic conditions without access to appropriate data. The same is true of occupational exposures. There have been examples in which agencies responsible for tracking occupational diseases have not shared data (despite the absence of a prohibition) with agencies responsible for

worker protection and workplace regulation (23). A review of the literature indicated that much of the failure to share information is due to poor planning rather than safety concerns. Programmes have experienced technical difficulties in sharing data, some data requiring conversion (e.g. birth year to age) in order to link databases (84, 85).

Public health systems should establish frameworks to enable secure sharing of data (see Guideline 10) with other national and international agencies. Early collaboration to align processes in order to avoid foregoing benefits or wasting resources is ethically warranted. Ethical frameworks for sharing should respect persons by ensuring that only the data required to fulfil a sufficiently important, legitimate public health purpose are shared, that data are not shared more broadly than necessary, and that data are not subsequently re-shared by other agencies, except under the conditions specified elsewhere in this document, e.g. in guidelines 16–17. When the protection of different datasets is not equivalent, the more stringent privacy standard should be applied.

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### **Guideline 15. During a public health emergency, it is imperative that all parties involved in surveillance share data in a timely fashion.**

The collection and sharing of data are essential activities in ordinary public health practice. During emergencies, data-sharing takes on increased importance because of the urgency of the situation, uncertainty in the face of incomplete or changing information, the compromised response capacity of local health systems and the heightened role of cross-border collaboration. For these reasons, “rapid data sharing is critical during an unfolding health emergency” (86). It not only constitutes good public health practice but is ethically imperative. Ethically appropriate, rapid sharing of data can help in identifying etiological factors; predicting disease spread; evaluating existing and novel treatment, symptomatic care and preventive measures; and guiding

the deployment of limited resources. As discussed in the WHO guidance on managing ethical issues in infectious disease outbreaks (49), clinical and research data that are crucial for emergency response should also be shared. Data-sharing is also an obligation under the IHR in both health emergencies and infectious disease outbreaks.

As part of continuous pre-epidemic preparedness, countries should review their laws, policies and practices on data sharing to ensure that they adequately protect the confidentiality of personal information and address other relevant ethical questions, such as settling disputes about the ownership or control of surveillance data. Efforts should be made to ensure that rapid sharing of surveillance information with immediate implications for protecting public health and advancing the common good should not preclude subsequent publication in a scientific journal (87).



Medical student and district surveillance officer investigating suspected Ebola cases in Western Region of Sierra Leone.

Source: WHO /Stéphane Saporito

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## **Guideline 16. With appropriate justification and safeguards, public health agencies may use or share surveillance data for research purposes.**

Surveillance data have often served as a foundation for important public health research (88-90). For example, cancer registries have been used in longitudinal epidemiological studies on survival and treatment efficacy. It may be permissible to share surveillance data with researchers undertaking studies that (i) are sufficiently important for advancement of the common good and (ii) would not be feasible without access to the surveillance data in question. There may sometimes be disagreement about what should be considered “sufficiently important” research to justify sharing of surveillance data for research purposes. This is a matter that local governments, public health authorities and/or research ethics committees (as described below) should judge, taking into account the considerations and guidelines set out in this document.

Sharing of surveillance data for research purposes requires appropriate safeguards, such as ethical oversight (see Guideline 2), anonymization, and data security. While the kind of ethical review required for conducting research is not appropriate for conducting public health surveillance, surveillance data should be shared only for research projects that have been reviewed and approved by an appropriate

research ethics committee or another appropriate body, consistent with international and local standards on the ethical conduct of research. In making decisions about granting access to surveillance data, ethics committees should consider the potential public health impact of research (Is the research sufficiently important, or does it have, in the language of CIOMS, “social value”?), the risks to the subjects involved, the measures in place to protect privacy, and the importance and feasibility of seeking consent.

Striking the appropriate balance between safeguards and research advancement will sometimes be challenging. One controversial way of sharing sensitive information on drug use has been to delete any information on substance use disorders from individual clinical records released to researchers. Such protection in the name of privacy has become the centre of controversy in the context of a wide-reaching opioid epidemic. One group of critics has argued that this has left researchers “flying blind” (91).

Researchers who have been provided with surveillance data should inform public health authorities about their findings. Before surveillance data are shared with researchers, there should be agreement about: appropriate data uses, restrictions on data re-sharing, adequate acknowledgement of the data source in publications, and data destruction conditions at the end of the research phase.

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## **Guideline 17. Personally identifiable surveillance data should not be shared with agencies that are likely to use them to take action against individuals or for uses unrelated to public health.**

While aggregate public health data may be widely shared with agencies outside the health sector and non-state actors responsible for public welfare, sharing personally *identifiable* data is a fundamentally different matter. Access to such personal information by agencies responsible for national security, law enforcement, or the allocation of social benefits should usually be allowed only after legal due process. To preserve trust in public health surveillance systems, there should be compelling justification for sharing identifiable data for non-public health uses.

Inappropriate sharing of surveillance data is especially controversial in countries in which law enforcement or other agencies have been

implicated in systematic violations of human rights. In these contexts, collaboration with law enforcement agencies may undermine trust in public health surveillance, creating a disincentive for seeking care or honest reporting of data. This is a particular concern for individuals or groups in situations of particular vulnerability (92). Further, such unwarranted sharing will potentially inflict long-term damage on public health efforts more broadly.

The governance mechanisms recommended in Guideline 2 should ensure that the exceptional conditions, if any, under which identifiable surveillance data may be shared are specified and made transparent. Such a review will require determination of whether the threat is of sufficient magnitude to warrant potential damage to the integrity of and trust in public health surveillance systems. Sanctions must be in place to prevent inappropriate data-sharing by public health agencies and inappropriate use of data by agencies outside the public health sector.



WHO Immunization officers visit Quang Binh Province, Viet Nam to monitor the Measles-Rubella immunization campaign.

Source: WHO / WPRO /Emmanuel Eraly



A barcode is placed at the entrance of houses. After being flashed with a smartphone, the barcode provides information about whether the house was controlled and declared dengue free or not.

Source: WHO/TDR /Catalina Cardenas

## V. The shifting boundaries of surveillance

Various “non-State” actors are involved in public health surveillance, including NGOs, faith-based organizations, professional organizations, research institutions, funding agencies, and supranational agencies like WHO and the European Centre for Disease Prevention and Control. Public surveillance functions may even be outsourced to private companies. This may be a cause of concern, as the data may no longer be owned by and accessible to State agencies. Nevertheless, the vicissitudes of surveillance mean that any set of ethical guidelines must cross boundaries – not only national boundaries but lines that have traditionally separated the public from the private (93).

The problem of blurred boundaries has become even more complicated in the era of big data. By “big data”, we refer to both the increased volume of data that can now be collected and stored, usually in digital form, and the computational power available to process it rapidly. The ubiquitous use of personal computers, smartphones, wearable devices, closed-circuit cameras, genetic sequencers, semi-autonomous drones, and other technologies means that we produce a steady stream of digital data.

A data-centric technological revolution has generated great enthusiasm about the emerging potential benefits of mining electronic health records, genomic data and other biological materials, social media communications, satellite imagery and other digital datasets to identify emerging disease threats, interrupt foodborne disease outbreaks and improve collaboration among public health organizations. Drones have been hailed as a “game changer” in disease surveillance. Some have argued that

drones could uniquely pinpoint an outbreak by identifying a rapid population exodus from a disease zone (94-96). Others are sceptical about “drone utopianism”, arguing that drone surveillance should not be a health priority for countries with limited resources (97).

Other new technologies, such as phylogenetic analysis of HIV, hold similar promise and peril, involving both use and failure to use data. Individuals who generate information through personal devices are probably unaware of the range of potential subsequent uses of their data. It is unclear whether the private sector has an obligation to share those data with public health or government officials. Custodians of such data should be aware of the issues that could arise and be involved in discussions about legitimate data-sharing and the steps that should be taken to monitor risk and prevent harm.

There have been mounting calls for additional research and ethical analysis on issues related to big data (98). The place of big data and digital disease detection in the public health surveillance landscape remains undetermined, and additional work should be done on privacy and anonymity, the integration of public and private data sets and issues of data validity and reliability (99). The Deputy Director for Surveillance and Epidemiology at the Bill & Melinda Gates Foundation recently sounded an important call: “We need ethicists to be working on some of these problems.”

In order to remain proactive rather than reactive, addressing these issues must represent the next frontier. While these guidelines are a place to start in addressing issues at the intersection of surveillance and big data, the challenges of this swiftly changing environment should be subject to continuing analysis and ethical monitoring. This challenge must be taken up by the global community.



Sphere and continents with binary code zero – one.

Source: CC0 Public Domain

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- What is the ethical obligation to undertake public health surveillance?
- What are the risks of conducting disease surveillance? How should such risks be balanced against population level benefits?
- When and how must relevant communities be engaged in the development of surveillance plans?
- How should the confidentiality of surveillance data be protected?
- What are the ethical obligations to share relevant public health surveillance data across public health authorities? With public health researchers? With communities and individuals who have contributed to surveillance systems?
- Are there circumstances when data sharing must be strictly prohibited?
- What institutional mechanisms should be established to ensure ethical issues are systematically addressed prior to data collection, use, and dissemination?

These are core questions that those involved in public health surveillance have grappled with for more than a century. To address these and other pressing concerns an international group of experts has developed the *WHO Guidelines on Ethical Issues in Public Health Surveillance*. Based on a set of core ethical and policy considerations, these 17 guidelines establish the affirmative duties to undertake surveillance, share data, and engage communities, while recognizing the limits of surveillance. They will be applied in situations characterized by fundamental cultural, economic, and political variability. The goal, therefore, is to enable critical discussion about legitimate ethical tensions and trade-offs and the appropriate governance and oversight of surveillance.

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ISBN 978-92-4-151265-7



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