World Health Organization

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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. 25

Guideline 2. Countries have an obligation to develop appropriate, effective mechanisms to ensure ethical surveillance. 27

Guideline 3. Surveillance data should be collected only for a legitimate public health purpose 29

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. 30

Guideline 5. Planning for public health surveillance should be guided by transparent governmental priority-setting. 31

Guideline 6. The global community has an obligation to support countries that lack adequate resources to undertake surveillance. 32

Guideline 7. The values and concerns of communities should be taken into account in planning, implementing and using data from surveillance. 33

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. 34

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. 36

Guideline 10. Governments and others who hold surveillance data must ensure that identifiable data are appropriately secured. 37

Guideline 11. Under certain circumstances, the collection of names or identifiable data is justified.....38

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. 40

Guideline 13. Results of surveillance must be effectively communicated to relevant target audiences. 41

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. 43

Guideline 15. During a public health emergency, it is imperative that all parties involved in surveillance share data in a timely fashion. 44

Guideline 16. With appropriate justification and safeguards, public health agencies may use or share surveillance data for research purposes. 45

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. 46

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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 to help policymakers 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.

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