

## Research Project

### Ethics of Surveillance Data Use

#### **Project funded by own resources**

**Project title** Ethics of Surveillance Data Use

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#### **Organisation / Research unit**

Ethik / Bio- und Medizinethik (Elger)

**Project Website** <https://ibmb.unibas.ch/de/research/research-ethics/ethics-of-surveillance-data-use/>

**Project start** 01.02.2014

**Probable end** 28.02.2017

**Status** Completed

Data routinely collected as part of surveillance activities in public health (PH) is increasingly being used for research purposes. This occurs because activities such as the routine documentation of interventions and monitoring of epidemiological data, that characterize surveillance, offer representative or comprehensive data that can be used for later research. However, there is an increasing realization that because surveillance does not ordinarily warrant ethical requirements, the data gathered within it, which may subsequently be used for research, may not undergo ethical reflection either. There is also a conceptual challenge of differentiating between “research” and “non-research” in surveillance, so as to develop appropriate criteria for ethical distinctions. Questions on whether, which aspects and at what point research using surveillance data (RUSD) should fit in existing ethical frameworks, have also been inadequate. Currently, there is consensus that ethical reflection is important for all evidence-generating initiatives, whether or not they constitute formal research. However, questions on who is responsible for ethical judgments, and what processes are adequate for RUSD remain unanswered. Moreover, existing ethical frameworks that have been produced are either suited to PH initiatives or research but not to both, as is thought to be necessary in the case of RUSD. There is consequently, a dependence on extrapolations from research ethics frameworks and PH ethics guidelines for RUSD. The resultant imprecision of stakeholders’ interpretation, adaptation and implementation of ethical standards have potentially serious implications for research ethics goals and public accountability. The danger is that contemporary PH evidence generation and RUSD models in resource limited countries, such as Health and Demographic Surveillance Sites, may not be to meeting the right ethical standards, even when critical ethical issues are raised.

**Keywords** Surveillance, Data Use, public health,

#### **Financed by**

University funds

Other funds

## Add publication

### Published results

3706239, Anane-Sarpong, Evelyn; Wangmo, Tenzin; Sankoh, Osman; Tanner, Marcel; Elger, Bernice Simone, Application of Ethical Principles to Research using Public Health Data in The Global South: Perspectives from Africa, 1471-8847, Developing World Bioethics, Publication: JournalArticle (Originalarbeit in einer wissenschaftlichen Zeitschrift)

4133852, Anane-Sarpong, Evelyn; Wangmo, Tenzin; Ward, Claire; Sankoh, Osman; Tanner, Marcel; Elger, Bernice Simone, "You Cannot Collect Data Using Your Own Resources And Put It On Open Access": Perspectives From Africa About Public Health Data-Sharing, 1471-8731 ; 1471-8847, Developing world bioethics, Publication: JournalArticle (Originalarbeit in einer wissenschaftlichen Zeitschrift)

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