

## WHO Issues Guidelines on Ethical Issues Related To Public Health Surveillance

### Document Raises Key Concerns About Risks And Benefits In The Era Of New Technologies And Big Data

Both research and surveillance involve data collection on human subjects. For research subjects, there are guidelines and requirements designed to protect them. Not so for the subjects of surveillance. At least, not until now.

To fill this guidance gap, the World Health Organization has published

the first ever international framework to help policymakers and practitioners navigate the ethical issues presented by public health surveillance. The 56 page document contains 17 separate guidelines accompanied by several lines of commentary introducing and explaining each guideline.

*- Surveillance continues on page 2*



## A Timely Question--Can Epidemiology Improve Public Health?

### SER Symposium Organizers Seek To Find Out

Presumably, epidemiologists know the answer to the question – can epidemiology improve public health and would answer in the affirmative. However, Lydia Feinstein and Jessie Edwards of the University of North Carolina, the organizers of a symposium on this topic, were aware that epidemiologic data can get ignored in policy and program

implementation, i.e., lost in translation.

They convened speakers on such varied topics as antibacterial soaps, HIV and TB, and asbestos to explore the triumphs and failures of epidemiology. We interviewed Dr

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## ***-Surveillance cont'd from page 1***

The document overall provides a refresher course for epidemiologists seeking to familiarize themselves with all of the considerable benefits and potential risks of doing surveillance in the modern age. Some of the new technology which gives rise to big data or uses drones to conduct surveillance pose new ethical questions and dilemmas for public health scientists and practitioners.

According to WHO, "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."

The 17 guidelines are listed below.

**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.

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

**Guideline 3.** Surveillance data

should be collected only for a legitimate public health purpose.

**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.

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

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

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

**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.

**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.

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

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# Commentary Clarifies The Different Ways Of Working Together With Other Scientists

## Report From An SER Symposium

Special report by Robert A Hiatt

My colleagues, Qing Li, Noel Weiss and Muin Khoury and I put on a symposium on the last morning of the recent 50<sup>th</sup> Anniversary SER Meeting just completed in Seattle entitled “The Central Role of Epidemiology in Transdisciplinary and Translational Team Science”. It was surprisingly well attended for being at the end of a long program and discussion was lively.

The editor of The Epidemiology Monitor thought that readers might be interested in hearing about the topic of Transdisciplinary Science and that it would be instructive to make some comparisons to the points made by George Kaplan in his interview in the May issue about his popular new book “Growing Inequality – Bridging Complex Systems, Population Health, and Health Disparities” which he co-edited with Ana Diez-Roux, Carl Simon, and Sandro Galea.

<https://tinyurl.com/ybgp6v8u>

There are in fact some interesting similarities and differences.

### Definitions

Transdisciplinary science, for those who are not familiar with it, is an approach to complex research topics that brings together scientists from multiple, and frequently diverse, disciplines to address common problem, using a common framework of possible causation. The participants in this approach are encouraged to hold their own knowledge lightly, listen to the

the perspectives of others and seek, through open and trusting interactions, ways to come up with new knowledge, hypotheses and ideas that they may not have considered working alone or in their own disciplinary field.

It was described by Patricia Rosenfield in the mid 1990’s as distinguished from multidisciplinary science where scientists from multiple disciplines attacked a common problem, but stuck to their own skills and knowledge base and from interdisciplinary science where there was more interaction between team members, but still the contributions were coming primarily from their own disciplinary perspectives. Transdisciplinary science looks for a blending of ideas, novel approaches and unexpected new knowledge.

Transdisciplinary science has itself been a topic of study for some decades and the reader is referred to the work of Dan Stokols and Kara Hall who have both written extensively on the topic from their positions in the School of Social Ecology at University of California Irvine and the Nation Cancer Institute’s Division of Cancer Control and Population Sciences, respectively. The NCI has supported a number of large transdisciplinary initiatives starting in the early 2000’s on topics such as tobacco control, cancer communication, cancer population health and health disparities, energy balance and breast cancer and the

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*“There are in fact some interesting similarities and differences.”*

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*“Transdisciplinary science looks for a blending of ideas, novel approaches and unexpected new knowledge.”*

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- Clarify continues on page 6

*"...the promise of novel epidemiologic methods is often unrealized..."*

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

**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.

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

**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.

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

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

**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.

To read the full report or more about the individual guidelines, go to:

<https://tinyurl.com/y7hh2g6u> ■

Feinstein about the symposium to learn more about what insights were gained.

**Interview**

**EM:** A question you asked in your abstract was – can epidemiology improve public health? Why was that question timely in your opinion?

**Feinstein:** This question was timely because, in recent years, the SER meetings have placed a strong emphasis on developing causal inference methods that directly estimate intervention effects. These emerging 'consequentialist' approaches, so to speak, have expanded our ability to conduct epidemiologic studies with clear interpretations for public health policy and clinical practice. However, the promise of novel epidemiologic methods is often unrealized in the implementation of interventions in the field or in the development of new policy. The goal of our symposium was to showcase examples of epidemiologic studies that have been successfully translated into clinical practice or policy and to examine the different ways this process can unfold. Many of us tend to get stuck in this bubble of conducting secondary or simulated data analyses, with an end goal of getting our work published in a respectable scientific journal. I think it's important to take a step back sometimes and think about what it would take to actually get our results translated into public health action.

**EM:** Epidemiologic data are often not translated into policy or action. What are some main reasons for that in your opinion?

*"I think it's important to take a step back sometimes..."*

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## Career Challenges For Women In Epidemiology Discussed At SER Symposium

A recent paper and commentary published in *Epidemiology* by [Enrique Schisterman](#) and colleagues and [Reshma Jagsi](#), respectively, on the careers of women in science and epidemiology were catalysts for a special symposium at the recent SER meeting entitled "Gender Disparities in Citations in Epidemiology: Data Reflections, and Looking to the Future".

According to the organizers, Schisterman and [Sunni Mumford](#), "although more women are entering science-based fields, women biomedical scientists are on average still paid less, promoted less, are less likely to receive grant funding, and are more likely to leave their careers than men." The questions tackled by these investigators are whether or not these patterns are true for women in epidemiology. Data on the role and status of women were presented at the symposium and reflections made by departmental leaders and journal editors on the implications of current patterns discovered in the epidemiology profession.

### Current Evidence

According to Schisterman, survey investigations they designed to assess the representation of women in epidemiology societies, in editorial positions, in departmental positions, and by academic rank and other positions show there is a greater number of female than male epidemiologists and also more female epidemiology students. Female epidemiologists are younger and early career.

Schisterman also provided information about whether or not there are gender disparities in publication metrics in the top epidemiology journals. He reported first authors were more likely to be female during the 2008-2012 period studied while last authors were more likely to be male, and articles with male first and last authors were more likely to have their papers cited especially for highly cited articles. The organizers asked "If epidemiology continues to be practiced by a majority of women, it remains to be seen if these patterns will change over time, and the question arises as to whether or not this gender difference will balance differently over time." Some of the insights gained at the symposium and recapped by Schisterman are described below.

### Insights from the deans:

[Michelle Williams](#) opened with a simple saying: "What's important gets measured". While the data, demonstrating a bias in citations for women in epidemiology, are an important first step in addressing gender disparities, they create more questions than answers, and present an opportunity to further explore alternative explanations using mixed methods research. Dr. Williams also highlighted the "pipeline" issue, with an influx of junior female epidemiologists not met by a similar departure for senior faculty. Along with Dr. Williams, [Germaine Buck Louis](#) highlighted the importance of good citation practices, and a need for

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*"...articles with male first and last authors were more likely to have their papers cited especially for highly cited articles."*

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investigators to both improve their own citation practices and to focus on transmitting those practices to the next generation of epidemiologists through mentoring. Dr. Buck Louis also suggested that journals report their metrics on the gender distribution of authors of submitted as well as published manuscripts.

Insights from the chairs:

The department chairs drew their commentary from a pervasive gender bias in academics, and highlighted the importance of senior faculty in perpetuating or challenging gender biases in authorship practices. Andrew Olshan emphasized the power of senior faculty in decision-making across the board, and the need for departments to meet the challenge of discussing gender inequities. Diane Lauderdale challenged the audience to flip the question to how male scholars' higher status in academia could lead to disparities in authorship and citation practices, and suggested that some of the disparity may be due to men consolidating power through self-promotion and preference for male mentors and male-dominated research groups.

Insights from editors:

Timothy Lash noted that while only one of five editors at *Epidemiology* is female, women are better represented among associate editors, echoing the pipeline issue for women faculty. Citing the commentary in *Epidemiology* by Reshma Jagsi, Lash noted that a similar trend can be found among K awards, with men who receive K awards receiving further funding more often than

women. Lash echoed the concern that the pipeline bringing the next generation of women into epidemiologic research may not only be slow, but may actually be leaking. All this gave more than enough reason to follow Jagsi's recommendations for prompt actions institutions should take to promote equity in our field, including mentoring, bridge funding, and bias literacy programs. ■

*-Clarify cont'd from page 3*

environment. The approach invariably draws on the need for team science and the literature frequently uses team science and transdisciplinary science interchangeably.

Further, as we tried to emphasize in our symposium these approaches are oriented to applications in the service of translational science beyond "the bedside", a point that Muin Khoury has written about extensively. I like to make the distinction between these processes for epidemiologists by saying that translational science is often best achieved by teams using a transdisciplinary approach. I also think that epidemiologists are highly suited to being key participants if not leaders in transdisciplinary science.

**Similarities**

The similarities to the points that George Kaplan made in his interview last month include the interaction of scientists from multiple disciplines and the challenge of getting them to work together. Patience, time and the right settings are needed to get scientists to trust and understand each other's language and ways of thinking. Sometimes the same word (e.g., race) can mean different things to different

*- Clarify continues on page 10*

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*"...the process of tackling the complexity of disease causation in an interdisciplinary group is 'iterative' and 'time consuming' but essential."*

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**Feinstein:** There are many reasons, one being that many epidemiologists have never done public health field work and another reason being that many field workers have never done epidemiology. I think it's important for us to try to close that gap in both directions.

**EM:** Did your symposium discuss any of these reasons or identify new ones?

**Feinstein:** We did. We also discussed political barriers, funding priorities, and feasibility. It was also noted that sometimes epidemiologists study effects of interventions that could not be conducted in some settings, or aren't generalizable to particular target populations. As epidemiologists, we can certainly do more to ensure that our work is relevant and timely.

**EM:** How would you describe the relationship between epidemiology and implementation science? What is the latter doing that the former is not, if anything?

**Feinstein:** First of all, we should note that people and groups have their own definitions of "epidemiology" and "implementation science." We sought to point out how epidemiology can be more useful by addressing issues directly related to implementation of interventions. Usually, epidemiology estimates the effects of interventions assuming that those interventions can be replicated exactly and that all effect modifiers can be measured (and modeled).

Implementation science highlights reasons that interventions may not be implemented with high fidelity to the original design (for better or worse). When we, as epidemiologists, consider

implementation of our findings (in the forms of interventions or policies), we are forced to think about the assumptions underlying the generalizability of our results to specific settings, the feasibility of implementing that intervention or policy in the same way in other settings, and whether the proposed intervention optimizes some utility function (e.g., overall population health) over other candidate uses of the resources required for implementation.

**EM:** Did your symposium identify concrete ways in which epidemiology improved health?

**Feinstein:** Yes, our symposium provided a few examples. Michael Herce discussed how epidemiology can be used to evaluate interventions and refine them as needed to suite a specific setting. He applied this idea to enhance his field work in HIV clinics in Malawi and Zambia. Similarly, Allison Aiello discussed how her dissertation work on hand hygiene eventually led to significant policy changes, including the banning of antimicrobial soaps.

**EM:** Do you have any other comments you would like to make about your session that are not mentioned above.

**Feinstein:** My co-chair Jessie Edwards and I were really glad to have the opportunity to organize this session. We had a fantastic turn out and a strong showing from a wide range of individuals, including methodologists, those whose work focuses on addressing more substantive research questions, and public health field workers. Bringing together this sort of integrative audience is an important first step to improve our ability as epidemiologists to have a strong positive impact on public health. ■

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*"Implementation science highlights reasons that interventions may not be implemented with high fidelity..."*

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# Notes on People



**Honored:** Tim Jones, with the Pumphandle Award, from the Council of State and Territorial Epidemiologists (CSTE) in recognition of his outstanding achievement in the field of applied epidemiology. He has served as Tennessee state epidemiologist since 2007 and has investigated numerous outbreaks resulting in recalls, health improvements, and countless lives saved, according to CSTE. He currently serves as both state epidemiologist and an assistant commissioner of the communicable and environmental disease and emergency preparedness division.



**Honored:** Ellicott Matthay, with the Tyroler Student Prize Paper at SER. She is a PHD candidate at the University of California Berkeley. The award recognizes the best submitted paper by a student in a doctoral program with a major in epidemiology. Her current research is focused on the causes and consequences of community violence.



**Honored:** Polly Marchbanks, with the Distinguished Service to SER award, at its recent meeting in Seattle. Dr Marchbanks has been an active member of SER serving as a Member-at-Large of the Executive Committee, a local host for the annual meeting, and President. She coordinated and chaired the SER Late-Breaker Session for 22 years. She retired from a long career at CDC in 2015.



**Appointed:** Jerome Adams, as Surgeon General of the United States. According to APHA, Dr. Adams has extensive experience in health care and has worked on the front lines of public health in Indiana, and his status as a working physician will serve him well in leading our nation's health promotion and disease prevention efforts."

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## Information For "Notes on People"

The Epidemiology Monitor is always interested in information about fellow epidemiologists at all stages of their careers and lives. Please forward any information for future issues to:

[epimon@aol.com](mailto:epimon@aol.com) / 678.361.5170



# Notes on People



**Appointed:** Brenda Fitzgerald, as the new Director of the Centers for Disease Control and Prevention. Fitzgerald served as commissioner of the Georgia Department of Public Health since 2011. APHA President George Benjamin welcomed the appointment saying "Dr. Brenda Fitzgerald is a strong choice to lead the Centers for Disease Control and Prevention...from her work as a practicing obstetrician-gynecologist to her recent service as the commissioner of the Georgia Department of Public Health, Dr. Fitzgerald is more than prepared to face the health challenges of our time, including climate change, Zika, Ebola, and our growing burden of chronic disease. She has shown tremendous leadership in the fields of maternal and child health, making early childhood development a priority throughout her work in Georgia. "



**Honored:** Ken Rothman, with the Career Accomplishment award at this year's SER meeting. Dr Rothman's main career focus has been the development and teaching of the concepts and methods of epidemiologic research. He has written two epidemiologic textbooks and has served in an editorial capacity for many journals, including *Epidemiology* which he started. He is a Past President of the Society for Epidemiologic Research. He is currently a Distinguished Fellow at Research Triangle Institute.



**Appointed:** Jonathan Samet, as dean of the Colorado School of Public Health. A well-known epidemiologist, Samet is currently chair of the Department of Preventive Medicine at the University of Southern California and holds other key appointments. The Chancellor at the University of Colorado said "As its third dean, Dr. Samet, who brings the experience of a long and distinguished career in academic medicine and public health, is uniquely qualified to take the Colorado School of Public Health to new heights."



**Honored:** Jay Kaufman, with the Excellence in Education award given by SER for substantial contributions to the field of epidemiology through impact on the career trajectory of mentees, trainees, or students. Dr Kaufman is currently Professor and Canada Research Chair in Health Disparities in the Department of Epidemiology, Biostatistics and Occupational Health at McGill University (Montreal, Quebec).



**Honored:** Neal Goldstein, with the Lilienfeld Post-Doctoral Paper which recognizes outstanding postdoctoral research in epidemiology. To be eligible, the paper must have been written as part of the applicant's postdoctoral training in the 3 years leading up to the June meeting. Dr Goldstein is an infectious disease epidemiologist and research fellow at Christiana Care Health System and a research assistant professor at Drexel University.

*- Notes on People continues on page 10*

# Notes on People



**Honored:** Laura Rosella, with the Brian MacMahon Early Career award in recognition of substantial contributions to the field in less than 7 years since her terminal degree and her potential to become a future leader in epidemiology. She has authored 100 peer-reviewed publications in the area of public health, public health policy, and health services research. She currently holds a position at the Dalla Lana School of Public Health at the University of Toronto.

*-Clarify cont'd from page 6*

disciplines; sometimes the same concept has different words to express it. Having worked with George on a complex systems project, I know what he means when he says that the process of tackling the complexity of disease causation in an interdisciplinary group is “iterative” and “time consuming” but essential.

## Differences

The difference between complex systems thinking and transdisciplinary science is, I believe, in that the first seeks primarily to understand complex systems of causation as they occur in the real world...not by exploring a “series of independent causes”.

Transdisciplinary science is more of an approach to solving problems, which may or may not be complex. This approach may be in the service of understanding causal relationships or it may be to develop a policy solution facing population health where the causal relationships have not yet been worked out. One doesn't need to invoke the descriptor “transdisciplinary” to do what George and his colleagues have done in the Network on Inequality, Complexity and Health. However, I believe it is a useful concept for epidemiologists to consider as they seek new knowledge for the benefit of population health. ■

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The deadline for applications to be submitted is October 15, 2017 but the search remains open until the positions are filled. The anticipated start date is July 1, 2018. Informal inquiries may be submitted to [episearch@ph.ucla.edu](mailto:episearch@ph.ucla.edu).

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# University of Bern

## Institute of Social and Preventive Medicine (ISPM)

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### Director & Full Professor of Epidemiology and Public Health

The Faculty of Medicine at the University of Bern is one of five medical faculties in Switzerland. The Institute of Social and Preventive Medicine (ISPM) is a leading institute in the faculty, with an outstanding national and international reputation for excellence in research, methodology and teaching. ISPM aims to advance and disseminate knowledge to improve health and the prevention of disease in the population as well as in specific patient groups. Education, training, continuing professional development and the training of specialists in Public Health are integral to the ISPM's mission. The research of the ISPM influences health strategy at cantonal, national and international levels.

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For more information, please contact the president of the selection committee, Prof. Stephan Windecker, Director and Chief Physician in the Department of Cardiology at the University Hospital (E-mail: [stephan.windecker@insel.ch](mailto:stephan.windecker@insel.ch)). Applications must be submitted electronically no later than 2. August 2017 to the Office of the Dean of the Faculty of Medicine at the University of Bern at [bewerbungen@meddek.unibe.ch](mailto:bewerbungen@meddek.unibe.ch). Further information regarding required documentation can be found under: <https://tinyurl.com/ycdl9g2m> START DATE 1. OF JANUARY 2017 OR UPON AGREEMENT.



## Neuro-Epidemiologist Nutrition-Obesity Epidemiologist

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The Icahn School of Medicine at Mount Sinai is as an exciting institution where innovation and creativity is transforming education, research and healthcare. In the past 10 years Mount Sinai has risen in NIH funding to rank 15<sup>th</sup> among U.S. Medical Schools, substantially increased the number of research faculty, built new research facilities, and expanded its translational research enterprise. Mount Sinai is home to dozens of top-funded research departments and multidisciplinary institutes, centers, and laboratories bridging research education and clinical care with opportunity for collaboration including the [Diabetes, Obesity, and Metabolism Institute](#), [Institute for Personalized Medicine](#), [Tisch Cancer Institute](#), [Mount Sinai Diabetes Center](#), the [Mount Sinai Department of Population Health Science and Policy](#), [Icahn Institute for Genomics & Multiscale Biology](#) and the [Mount Sinai Department of Genetics and Genomic Science](#). Mount Sinai has a diverse patient population of 3 million patients spanning the socioeconomic spectrum, whose electronic medical records are available for research via the [Mount Sinai Data Warehouse](#) and can be linked to biorepositories such as [BioMe](#).

**To Apply:** Please send CV and three references to Dr. Emanuela Taioli, Director of ITE at [emanuela.Taioli@mountsinai.org](mailto:emanuela.Taioli@mountsinai.org).



University of Pittsburgh

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