Annals of Epidemiology 34 (2019) 1–5

Contents lists available at ScienceDirect

Annals of Epidemiology

From the American College of Epidemiology

Untangling the ethical intersection of epidemiology, human subjects research, and public health

Jennifer Salerno, PhD, MSc [a, *], Edward S. Peters, DMD, SM, ScD [b],
Susan M. Pinney, PhD, FACE [c], Stephanie Morain, PhD, MPH [d],
WayWay M. Hlaing, MBBS, MS, PhD, FACE [e]

[a] *Aging, Community and Health Research Unit, School of Nursing, McMaster University, Hamilton, Ontario, Canada*
[b] *Epidemiology Program, School of Public Health, Louisiana State University, New Orleans*
[c] *Department of Environmental Health, College of Medicine, University of Cincinnati, Cincinnati, OH*
[d] *Center for Medical Ethics and Health Policy, Baylor College of Medicine, Houston, TX*
[e] *Division of Epidemiology and Population Sciences, Department of Public Health Sciences, University of Miami, Miami, FL*

ARTICLE INFO

Article history:
Received 23 October 2018
Accepted 15 March 2019
Available online 27 March 2019

Keywords:
Biomarkers
Epidemiology
Ethics
Interventions
Public Health
Population Registries
Zika virus

ABSTRACT

Purpose: Members of the American College of Epidemiology (ACE) Ethics Committee identified current ethics and epidemiology topic areas to consider for further discussion, consultation, teaching opportunities, and conference presentation. This article reflects on the activities of the Committee at the ACE Annual Meeting in New Orleans, Louisiana, September 24–26, 2017.

Methods: The overall aim for the Ethics Committee was to engage members of the College and other audiences and highlight the evolution of ethics and epidemiology since the inception of the original Ethics Guidelines published by the ACE Ethics and Standards of Practice Committee in 2000. The Ethics Committee organized a symposium session at the 2017 Annual Meeting of ACE on the ethics of human subjects research as it relates to specialized areas of epidemiology and the intersecting role of public health. This article presents a summary and further discussion of that symposium session.

Results: Three topic areas were presented: an overview of ethics and epidemiology (E.S.P.), very high biomarker levels in environmental epidemiology research (S.M.P.), and the interface of epidemiology, human subjects research, and public health interventions (S.M.). This article begins by reviewing the foundations of epidemiology and public health and the well-known ethical principles of human subjects research. Then, it considers the ethical considerations in the use of population registry data in epidemiological research, environmental epidemiology, and epidemic surveillance and response. This article may form the basis of teaching of ethics principles related to epidemiology and public health and may serve as a companion piece to the original ACE Ethics Guidelines.

Conclusions: Researchers are increasingly faced with ethical considerations in diverse, nontraditional, and specialized areas of epidemiology and public health. This article illustrates these challenges with real-world examples of clinical and population registry data, the study of environmental biomarkers, and Zika virus epidemic; it also reviews relevant ethical principles underpinning these examples and identifies where gaps in knowledge may exist.

Introduction

The ethical intersection between epidemiology and public health relates to the roots of each of these fields of practice. In an attempt to untangle the intersection, it is helpful to briefly consider the scope of research and practice in each of these domains. The field of epidemiology is most notably embedded within population health alongside other disciplines (e.g., behavioral health) who study populations, but epidemiology is considered the core scientific discipline of population health. Population health is a conceptual framework for thinking about why some people are healthier than others, often using the following four objectives for studying the health of populations: to describe, to explain, to predict, and to control disease [1]. Epidemiology is defined as the study

---

* Corresponding author. Aging, Community and Health Research Unit, School of Nursing, McMaster University, 1280 Main Street West, Office 3N25D, Hamilton, Ontario L8S 4K1, Canada. Tel.: +1-905-525-9140x20019.
E-mail address: salernoj@mcmaster.ca (J. Salerno).

https://doi.org/10.1016/j.annepidem.2019.03.009
1047-2797/© 2019 Elsevier Inc. All rights reserved.

of the distribution and determinants of health and disease in populations, and the application of this scientific knowledge to improve the public's health and the health of populations [2]. Public health practice is concerned with health promotion and disease prevention of populations in communities. Areas of focus in public health are healthy lifestyles, communicable disease control (e.g., sexually transmitted diseases), immunization, food safety, healthy growth and development, health education across the lifespan, and screening services [3,4]. The application of epidemiology methods is used to improve the public's health: when data are collected in population registries for use in disease and injury surveillance and those results are reported and when knowledge is synthesized and translated regarding effective public health interventions [5,6]. Therefore, the science of epidemiology contributes to the practice of population and public health.

The intersection of epidemiology and public health typically leads to epidemiologists contemplating ethical and scientific decision-making at all stages of research and practice. There is often little discussion or guidance on the ethical reasoning required, especially in diverse, nontraditional, and specialized areas of epidemiology and public health. Ethical reasoning plays a role in many epidemiologic areas; from consideration of the study design, methods, data collection/analysis to the application of research content as in program planning, evidence-based practice, knowledge translation, and communication of findings. The American College of Epidemiology (ACE) Ethics Committee hosted a symposium session at the 2017 Annual Meeting in New Orleans, LA, September 24–26, 2017 to highlight the intersection of epidemiology and public health from an ethics standpoint. Researchers in specialized and nontraditional areas of epidemiology and public health are the intended audience for this article. This article deals with the ethical intersection of epidemiology, human subjects research, and public health and attempts to offer guidance to epidemiologists when challenged with ethical reasoning under conditions of uncertainty.

Overview of ethics and epidemiology

Epidemiology is the design and conduct of scientific research and the public health application of scientific knowledge. Relevant activities include reporting results to the scientific community, study participants, and society. A number of guidelines can inform the epidemiologist about ethical principles, standards, and procedures, including ACE Guidelines (https://www.acepidemiology.org/), International Society for Environmental Epidemiology (https://www.iseepi.org/), International Epidemiological Association (http://ieaweb.org/), and the Council for International Organizations of Medical Sciences (https://cioms.ch/).

At the heart of the professional practice of epidemiology are the core values and duties of the discipline as outlined in the 2000 ACE Ethics Guidelines including the professional practice values of honesty, prudence, excellence, and integrity. Key duties and obligations define how and for whom we should act, including (1) minimizing risks and protecting the welfare of research participants, (2) providing participant benefits, (3) ensuring an equitable distribution of risks and benefits, (4) protecting confidentiality and privacy, (5) obtaining the informed consent of participants, (6) submitting proposed studies for ethical review, (7) maintaining public trust, (8) avoiding conflicts of interest and partiality, (9) communicating ethical requirements and confronting unacceptable conduct, and (10) obligations to communities [7].

The link between epidemiology and human subjects research is the pursuit of scientific knowledge applicable to human health and well-being. Research can be defined as “a systematic investigation, including research development, testing, and evaluation, designed to develop or contribute to generalizable knowledge” [8]. Human subjects research is when a “living individual” (human subject) encounters a researcher (whether professional or student) conducting the research, either directly, by means of intervention or one-to-one interaction (e.g., data collection), or indirectly, such as when the researcher obtains identifiable private information about living individuals [9]. The Belmont Report [8] provides the philosophical underpinnings of 2018 U.S. Federal laws governing research involving human subjects and Canada's policy on research involving human subjects including the requirement that research must undergo review by an ethics board [9,10]. The ACE also endorses the three ethical principles described in the Report: (1) respect for persons, including respect for autonomy and the protection of those with diminished autonomy (which guides informed consent), (2) beneficence: protect research subjects from harm (assessment of risks/benefits), and (3) distributive justice which requires that the selection of subjects should be equitable and unbiased such that a population that bears the burden of research should, generally, be the same as the population that benefits from the research [7,8].

Participant recruitment and use of population registries

A key challenge in working with population registry data is to balance the needs of individuals and researchers. For our discussions, a population registry is an organized collection of uniform data on a population defined by a particular disease or health condition with the aim of addressing clinical or other outcomes for the population by which the registry is defined [11]. For our discussions, this includes population registries in which patient-identifiable information exists and for which research investigators are required to apply for authorized access to the population registry. In the context of epidemiological research, the ethical principle of respect for persons requires researchers to protect privacy and confidentiality according to the study designs and procedures for which a participant has consented. The use of population registry data in of itself is a beneficial public health activity; it promotes the scientific usefulness and value of the population registry, for which resources have been invested, and can contribute toward enhancing scientific knowledge to improve the public's health.

When using population registries in research studies, there is occasionally an interest on the part of the researcher to contact patients to be able to then follow-up with patients and administer a questionnaire or conduct interviews as part of the data collection procedures in their research study. This requires the researcher to obtain the required institutional review board approvals for their research methods. The role of the treating physician for patients who already exist in the population registry then becomes a special area for discussion. For some health conditions and research studies (e.g., population-based cancer registry), when an eligible patient is identified from the population registry, there may be a requirement placed on the researcher to seek active treating physician permission before researchers can contact patients. This approach offers potential advantages: that the treating physician can help manage privacy risks and exclude at the outset patients who are deceased, too ill, or otherwise ineligible. When seeking such active physician's permission, a nonresponse from the physician is often considered a status of passive refusal in the research context. In other research instances, researchers only have to notify the treating physician of planned patient contact; seeking active notification from physicians of such contact may be contraindicated. In such cases, the nonresponse from the physician is considered to be passive permission in this research context [12]. After this passive permission, patient contact can occur, including sending potential patients an introductory letter/package about a research study. After receiving an introductory letter about a research study, potential patients may then be enrolled in the research study in one of two ways, either by (1) opt-in approach, whereby researchers follow-up only with those patients who take action (e.g., return a postcard from the introductory letter/package) to indicate their interest in the research study or (2) opt-out approach, whereby researchers follow up with all patients except those who have decided to opt-out of further contact from the researcher by communicating (e.g., returned postcard) such decision.

The implications of different recruitment strategies include placing the physician in the role of “gatekeeper” and differential “contact proportions” depending on whether the physician is taking an active or passive role [13–15]. There is the ethical concern as it relates to the principle of justice—having the physician as gatekeeper may differentially influence patient accrual in otherwise beneficial research. When researchers recruit participants through population registries, an individual may perceive that his or her privacy has been invaded because the researcher gained access to personal information before that person has consented to participate in the research, although it may not necessarily result in any harm to the individual. Researchers need to consider these aspects as they relate to their study design (e.g., sampling methods, sample size determination, analysis) and potential biases (e.g., selection bias), as well as the need for researchers planning to use population registries for research studies to plan for appropriate institutional review board review and approvals. In the example of the use of population registry data in epidemiological research, the choice of the scientific method has an impact on the ethical considerations, including the following: (1) respect for autonomy, (2) beneficence, (3) overprotection and paternalism, (4) issues of privacy and confidentiality, (5) justice, and (6) submitting proposed studies for ethics review.

Environmental epidemiology research

Many epidemiological research studies measure environmental biomarkers in human samples. Exposure to environmental chemicals may have known or unknown health effects, and some individuals are found to have very high concentrations of environmental biomarkers in blood or urine. For our discussions, these “extreme” values of environmental biomarkers signify what is referred to as “incidental findings,” defined as unanticipated but potentially impactful findings that are detected as part of the research but findings that are considered out-of-scope of the originally intended aims of the particular research study [15]. The increasing rise of incidental findings of extreme environmental biomarkers is owed in part to advances in technology and the ability to generate vast amounts of research data. The challenge for epidemiologists is that there is currently a lack of guidance and standard of practice for researchers when they are faced with these types of findings in the research setting [16]. Epidemiologists are struggling with what may constitute “usual practice” and the resulting ethical considerations. Responses may be variable and limited in a number of ways, such as (1) researchers may (or may not) report back exposure biomarkers levels to study participants, (2) research studies usually do not make allowance for follow-up with participant's physicians or community public health officials, (3) research analytes are typically measured long after the sample was collected; therefore, the relevance to current internal exposure is not entirely known and is dependent on the analyte's half-life, (4) the relationship between the analyte and any adverse health effects may not yet be well-established, and (5) relevance of an analyte level to current health is usually unknown. If physicians or public health officials were given the incidental study findings of very high exposure levels of environmental biomarkers, would there be any benefits to research participants in terms of (1) identifying the exposure source to reduce exposures, (2) discovering clinical conditions, (3) resolving undiagnosed illness or preillness, and (4) receiving intervention(s) to reduce exposure levels.

The considerations stemming from the detection of incidental findings of extreme environmental biomarkers in research studies in many ways align with epidemiologists' duties as they relate to individual study findings. Incidental study findings of very high levels of biomarker exposures and the uncertainty for researchers surrounding how and what to communicate relate to the principles of respect for autonomy including duties of informed consent, justice, and the principle of beneficence. In the following, we suggest some proactive approaches that researchers can take that promote the responsible consideration of incidental findings of extreme environmental biomarkers [17,18]. At the onset of study design, it is preferable for the researcher to consider how, what, and to whom incidental research findings of extreme environmental biomarkers will be communicated and build the decision-making capacity into the informed consent process, thereby allowing the research study participant to determine the outcome and be active participants. Timely and transparent sharing of knowledge by researchers that also aims to avoid or minimize psychological distress for research study participants is potentially beneficial, even if the researcher's knowledge is yet to be comprehensive, that is, knowing all the risks, benefits, and health effects. A suggested approach is to offer research study participants the opportunity to be informed of their study results of incidental findings of extreme environmental biomarkers as to the best of the researchers' ability and be offered to have their corresponding physician or public health official informed of their study results for appropriate follow-up if needed. Study participants have almost uniformly indicated that they would like to receive their individual biomarker results but tend not to share the information with their physicians [19]. Giving this choice to the research study participants instead of the researcher, physician, or public health official strengthens participant's autonomy and circumvents the situation of others acting as their gatekeepers. The trade-offs with these suggested approaches are the known and unknown complexities and costs of appropriately consenting patients in research studies, the a priori knowledge needed by the researchers for the potential to uncover incidental findings of extreme environmental biomarkers, and the costs associated with sharing of research results to study participants, including the ability of researchers to minimize any potential for harm to study participants. The demonstration of transparency that derives from communication of incidental study findings of extreme environmental biomarkers aligns with good professional practice, increases trust in the research community, and implies the obligations of epidemiologists to their research study participants according to the following duties: (1) conduct valid and reliable research, adhering to the highest scientific standards, and provide appropriate interpretation of results and levels of uncertainty, (2) provide sufficient details to facilitate understanding, (3) develop communication skills, and (4) distinguish between group and individual results, overall results, measures of risk, and inferences that can be made [20]. The goal of the epidemiologist conducting the environmental epidemiology research is to obtain truly informed consent from their research study participants while also balancing the risks and benefits of sharing exposure biomarker levels in the light of scientific uncertainty about the exposures and potential health effects and of protecting research participants and communities from harms. Epidemiologists who elect not to return these extreme values to study participants may be doing harm. For example, by not presenting the opportunity to reduce exposure, not allowing the physician to incorporate the information in his/her care, and by not providing public health officials the opportunity to remove an exposure source that may be affecting individuals and communities. Notwithstanding the recommendations described previously for what epidemiologists ought to consider in their research endeavors, it is noteworthy to mention that the actionable and planning steps for the handling of different types of incidental findings and the boundary between research and clinical care has not achieved widespread consensus [21,22].

Interface of ethics, epidemiology, and public health interventions

Historically, decisions about ethical oversight for research have relied on the “distinctions paradigm” [23]. Several features of the contemporary landscape challenge the appropriateness of the distinctions paradigm, including (1) the rise of learning health systems, which, by design, deliberately integrate research and clinical practice with the aim of improving the quality and efficiency of care and the relevance of research, (2) pragmatic clinical trials, which are often conducted in the context of everyday clinical care, and (3) the increasing ability of health systems to collect, aggregate, and analyze vast quantities of data, which are used for multiple, diverse purposes, including quality improvement, individual patient care, population health management, and research. These challenges present conceptual, moral, and practical problems [23].

The notion of a clear-cut research-practice distinction for epidemiology and public health, where epidemiology is considered research and public health is considered practice, has long been recognized as a poor fit. To this end, there have been various efforts to delineate the research-practice distinction in the context of public health and epidemiological research: Centres for Disease Control and Prevention Policy on distinguishing public health research from nonresearch [24], 1991, 2009 Council for International Organizations of Medical Sciences (https://cioms.ch/), 2007 Nuffield Council (http://nuffieldbioethics.org/), and the World Health Organization Guidelines on Public Health Surveillance [25]. The demand for more meaningful research [26] and increased translation of research to practice [27,28] has led to multistaged activities that interconnect research, public health practice, and policy. A single lens approach (i.e., intent-based model) to guide ethical oversight is limited to serving only as a starting point [29]. New technologies also challenge existing paradigms for research oversight such as the potential for genetic modification of animal vectors including mice and mosquitoes to reduce the burden of infectious disease. Field tests of these technologies will require examination of such thorny issues as what constitutes human subjects research in this context? When is individual consent needed? What is the role of community consultation and consent in deciding whether these trials go forward? Ultimately, we should consider moving toward a more adaptive system of ethical oversight rather than a one-size-fits-all model.

Case study: Zika virus

The Zika epidemic provides an illustrative case study of several contemporary challenges related to ethics, public health, and epidemiology. One challenge relates to testing in the face of an emerging infectious disease: is it clinical practice, research, or public health? We suggest Zika virus testing has value for all three types of activities. Clinically, testing for Zika virus offers diagnostic information. It may also inform reproductive and clinical decision-making, from decisions about contraceptive use and family planning to those related to subsequent fetal testing, including the use of amniocentesis. For public health, testing provides essential information related to disease incidence and prevalence, informing such assessments as to whether a case resulted from local transmission, sexual transmission, or travel and related implications for travel guidance, risk communication, and geographic resource distribution. For research, testing provides critical information for epidemiologic studies such as providing data for studies assessing risk by gestational age, perinatal transmission rates, and natural history of Zika virus infection. Not recognizing the value of testing in more than one context can result in ethical and practical shortcomings. For example, clinicians described occasionally declining to share Zika testing results with public health departments, citing respect for patient autonomy and patient privacy. This suggests at least some clinicians may have viewed testing only as a clinical activity without realizing its value for either public health or epidemiological research. This underestimation of the wide-scale applicability of Zika testing suggests the need for future scholarship and training to improve awareness of the way in which a single activity may inform research, clinical practice, and public health. Currently, the Zika virus is a reportable condition [30].

Conclusions

We have tried to argue that the untangling we seek might begin by recognizing the foundational similarities and differences in the scientific domains of epidemiology and public health. The question remains: do current ethics guidelines and frameworks serve multiple functions—clinical, epidemiology, and public health? In this article, we have only explored the tip of the iceberg of such broad areas of epidemiology and public health as it relates to research and practice. In the process, we recognize that some of what is considered public health (e.g., surveillance) includes activities of epidemiology, whereas the study of public health interventions derives concepts from epidemiologic study designs such as randomized controlled trials. The untangling we seek involves the extent to which a medical ethics lens serves epidemiology and public health. This article has highlighted that in specialized areas of epidemiology, a current ethical analysis is needed.

This article has demonstrated the need for ethical reasoning in some areas of epidemiologic research, from consideration of participant recruitment from population registries to the communication of incidental findings of extreme environmental biomarkers, and communicable diseases. Epidemiologists should uphold the additional “principles” of accountability, honesty, and transparency and their duties and obligations to their research study participants and communities by adhering to the highest scientific standards and having clearly defined protocols, study design, and informed consent processes; thresholds for incidental findings of extreme environmental biomarkers; ethical review; protection of study participants from unnecessary risks including anxiety and financial burden; involving communities and their representatives in research (i.e., engagement and participatory methods); and allowing for the widest possibilities for benefits, including clearly defined plans for follow-up and risk communication. We encourage all epidemiologists to take a step back and consider an ethical analysis for new and emerging challenges. Each one of us should continue to challenge and bring forward the ethical principles that bear on the individual patient, population, and the community.

Acknowledgment

The authors thank Dr. Ken Goodman for his helpful comments on previous draft versions of this article. This article reflects the

views of the authors and it does not necessarily reflect the opinions of the American College of Epidemiology (ACE) or the authors' affiliated institutions.

References

[1] Young KT. Chapter 1: introduction. In: Population health: concepts and methods. 2nd ed. New York (NY): Oxford University Press; 2005. p. 1–24.

[2] Last JM. A dictionary of epidemiology. 4th ed. New York (NY): Oxford University Press; 2001.

[3] American Public Health Association. What is public health. https://www.apha.org/what-is-public-health. [Accessed 5 February 2019].

[4] Ontario Ministry of Health and Long-Term Care. Health services in your community. http://www.health.gov.on.ca/en/common/system/services/phu/. [Accessed 5 February 2019].

[5] Kass NE. An ethics framework for public health. Am J Public Health 2001;91(11):1776–82.

[6] Cullum N, Ciliska D, Haynes BR, Marks S. Evidence-based nursing: an introduction. Oxford, UK: Blackwell Publishing; 2008.

[7] American College of Epidemiology. American College of Epidemiology ethics guidelines. https://www.acepidemiology.org/ethics-guidelines. [Accessed 5 February 2019].

[8] The National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research. The Belmont report: ethical principles and guidelines for the protection of human subjects of research. Washington DC: U.S. Department of Health, Education, and Welfare; 1979.

[9] U.S. Department of Health & Human Services. Part 46 - protection of human subjects. https://www.ecfr.gov/cgi-bin/text-idx?m=10&d=22&y=2018&cd=20181018&submit=GO&SID=83cd09e1c0f5c6937cd9d7513160fc3f&node=pt45.1.46&pd=20180719. [Accessed 5 February 2019].

[10] Canadian Institutes of Health, Research Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada. Tri-council policy statement: ethical conduct for research involving humans. Ottawa, Canada: Government of Canada; 2014.

[11] Gliklich RE, Dreyer NA, Leavy MB, editors. Registries for evaluating patient outcomes: a user's guide. 3rd ed 2014. https://www.ncbi.nlm.nih.gov/books/NBK208625/. [Accessed 5 February 2019].

[12] Meslin EM. The recruitment of research participants and the role of the treating physician. Med Care 2001;39(12):1270–2.

[13] Clinton-McHarg T, Carey M, Sanson-Fisher R, Tracey E. Recruitment of representative samples for low incidence cancer populations: do registries deliver? BMC Med Res Methodol 2011;11(1):5.

[14] Beskow LM, Sandler RS, Weinberger M. Research recruitment through US central cancer registries: balancing privacy and scientific issues. Am J Public Health 2006;96(11):1920–6.

[15] Gurwitz JH, Guadagnoli E, Landrum MB, Silliman RA, Wolf R, Weeks JC. The treating physician as active gatekeeper in the recruitment of research subjects. Med Care 2001;39(12):1339–44.

[16] Wolf SM, Lawrenz FP, Nelson CA, Kahn JP, Cho MK, Clayton EW, et al. Managing incidental findings in human subjects research: analysis and recommendations. J Law Med Ethics 2008;36(2):219–48. 211.

[17] Morello-Frosch R, Varshavsky J, Liboiron M, Brown P, Brody JG. Communicating results in post-Belmont era biomonitoring studies: lessons from genetics and neuroimaging research. Environ Res 2015;136:363–72.

[18] Brody JG, Dunagan SC, Morello-Frosch R, Brown P, Patton S, Rudel RA. Reporting individual results for biomonitoring and environmental exposures: lessons learned from environmental communication case studies. Environ Health 2014;13:40.

[19] Giannini CM, Herrick RL, Buckholz JM, Daniels AR, Biro FM, Pinney SM. Comprehension and perceptions of study participants upon receiving perfluoroalkyl substance exposure biomarker results. J Ind Hyg Public Health 2018;221:1040–6.

[20] Coughlin S, Beauchamp TL, Weed DL. Chapter 7: ethical issues in the interaction with research subjects and the disclosure of results. In: Ethics and epidemiology. 2nd ed. New York (NY): Oxford University Press; 2009.

[21] Wolf SM. Return of individual research results and incidental findings: facing the challenges of translational science. Annu Rev Genomics Hum Genet 2013;14:557–77.

[22] Wolf SM. Introduction: the challenge of incidental findings. J Law Med Ethics 2008;36(2):216–8.

[23] IOM (Institute of Medicine). Integrating research and practice: Health system leaders working toward high-value care: Workshop summary. Washington (DC): The National Academies Press; 2015.

[24] Centers for Disease Control and Prevention. Distinguishing public health research and public health nonresearch. https://www.cdc.gov/od/science/integrity/docs/cdc-policy-distinguishing-public-health-research-nonresearch.pdf. [Accessed 5 February 2019].

[25] World Health Organization. WHO guidelines on public health surveillance. https://www.who.int/ethics/publications/public-health-surveillance/en/. [Accessed 5 February 2019].

[26] Farmanova E, Kirvan C, Verma J, Mukerji G, Akunov N, Phillips K, et al. Triple aim in Canada: Developing capacity to lead to better health, care and cost. Int J Qual Health Care 2016;28(6):830–7.

[27] Brown CH, Curran G, Palinkas LA, Aarons GA, Wells KB, Jones L, et al. An overview of research and evaluation designs for dissemination and implementation. Annu Rev Public Health 2017;38:1–22.

[28] Wolfenden L, Williams CM, Wiggers J, Nathan N, Yoong SL. Improving the translation of health promotion interventions using effectiveness-implementation hybrid designs in program evaluations. Health Promot J Austr 2016;27(3):204–7.

[29] Coughlin SS. Ethical issues in epidemiologic research and public health practice. Emerg Themes Epidemiol 2006;3:16.

[30] Centers for Disease Control and Prevention. National notifiable conditions. 2018. https://wwwn.cdc.gov/nndss/conditions/notifiable/2018/. [Accessed 5 February 2019].