

Ethical issues in public health surveillance: drawing inspiration from ethical frameworks

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Abstract

The issues raised by public health surveillance are typical of those involved in public health ethics. Surveillance calls, in particular, for the balancing of individual rights and collective interests, which are often in conflict. One of the issues most closely linked with public health surveillance is the collection and use of personal data for purposes of public concern. Numerous frameworks (proposed by institutions, working groups or single individuals) are available for use in assessing the ethical correctness of public health interventions in general or, more specifically, of public health surveillance. While heterogeneous in nature, these frameworks are nonetheless built on a foundation of common values that are similar to those typically encountered in a clinical setting and to which bioethics has traditionally devoted considerable attention. However, it is necessary to apply these values to the specific context of public health, where the focus is more on the interests of the public at large than on those of the individual.

Key words

- bioethics
- health surveillance
- guidelines
- public health

THE CONTEXT: PUBLIC HEALTH, SURVEILLANCE AND ETHICS

In order to focus on the ethical problems posed by public health surveillance a brief illustration of the context is helpful. According to the US Institute of Medicine (IOM) “public health is what we, as a society, do collectively to assure the conditions in which people can be healthy” [1]. In the WHO’s definition “surveillance means the systematic ongoing 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” [2].

There are three basic steps to public health surveillance. The first is system development, which comprises two key activities: planning and design. The second step (data collection and analysis) comprises: data collection, collation, analysis and interpretation. The third step is data use, which involves the dissemination of the data collected and its application to public health programmes [3, 4].

Surveillance is recognised as “a foundational tool of public health, serving as the finger on the pulse of the health of a community” [4]. The role of surveillance in the management of public health is crucial, and it follows that the ethical problems it poses are both typical of public health ethics and of considerable significance. The conflict between individual and collective interests

is most evident in the control of infectious diseases. The spread of AIDS was historically the most powerful incentive to examine the issue more closely: “in contemporary public health, no condition has pushed us to think about how individual rights relate to public health more than HIV/AIDS” [4]. This conflict between individual and collective interests that is so typical of public health in general and of surveillance in particular poses challenges that differ from those normally encountered in bioethics. This is because bioethics focuses more on the individual patient and on the physician/patient relationship, while in the public health setting the “patient” is the public at large. One of the key questions for ethics in the field of public health surveillance is: “What are the justifications for limiting individual liberty in order to promote the public’s health as a common good?” [5]. The contrast appears so sharp as to make public health ethics and clinical ethics seem almost irreconcilable [6]. In actual fact, though, the basic ethical values are not dissimilar and are independent of whether the issue at stake arises within a clinical or a public health context [7]. It is, instead, the practical solutions that may differ, though the underlying values remain unchanged.

In public health ethics the approach to managing the conflict between individual and collective rights varies in accordance with the diverse schools of thought: utilitarianism aims to maximise the benefit for the greatest

possible number of people, regardless of its distribution, through the adoption of scientifically controlled measures [8]; deontology is guided by moral rules and principles [9]; egalitarianism stresses equal access to different goods and fairness among persons of different social backgrounds [10]; contractualism considers fair and morally right decisions based on procedural justice, in which the public is involved in the decision-making processes [11]; individualism gives priority to freedom and autonomy [12]; personalism aims to build the common good by promoting and making the most of the good of individuals while fostering solidarity [13].

The present article does not aim to discuss the theoretical foundations underlying the ethics of public health surveillance: it aims instead to examine some of the frameworks that offer practical suggestions for assessing the ethical propriety of measures.

ETHICAL FRAMEWORKS

A large number of heterogeneous frameworks are available on the subject, including codes, guidelines, checklists, lists of questions. They are drawn from equally varied sources: public institutions, scientific associations, groups of experts, individual authors, etc.

These frameworks are of considerable practical use, as they can be used to verify the agreement between ethical principles and proposed public health measures.

Of the few presented below, some are merely mentioned, others are examined briefly. The decision as to which should be examined more carefully was taken arbitrarily, with a view to highlighting those with more interesting ethical implications.

Some frameworks are concerned with public health in general but offer suggestions that may also be useful in the more specific setting of surveillance, while some are concerned specifically with surveillance.

General frameworks

Among the frameworks concerned with public health in general, some are actually codes, one notable example being the *Principles of the ethical practice of public health* issued by the American Public Health Association [14]. This document presents 12 such principles, which are intended to guide, but do not prescribe, specific actions. The guidance notes [15] that accompany the principles suggest that the code is intended to cover the entire field of public health, including but not limited to government institutions and schools of public health. Principle 1 lays down the goals for public health as principally addressing “the fundamental causes of disease and requirements for health, aiming to prevent adverse health outcomes”. This is reinforced in principle 5 which refers to “policies and programs that protect and promote health”. Principle 2 introduces the notion of “community health”, which recurs in subsequent principles. For instance: “policies, programs and priorities should be developed and evaluated through processes that ensure an opportunity for input from community members” (principle 3); “advocate and work for the empowerment of disenfranchised community members” (principle 4); “provide communities with the information they [public health providers] have that is needed

for decisions on policies or programs” and “obtain the community’s consent” (principle 6); “protect the confidentiality of information that can bring harm to an individual or community” (principle 10). However, the code fails to offer a precise definition of community, and this notion thus remains somewhat controversial [16].

Among the guidelines, one example is the *Ethics guidelines* issued by the American College of Epidemiology. After sketching the “professional role of epidemiologists” this document identifies the following points: minimizing risks and protecting the welfare of research participants; providing benefits, ensuring an equitable distribution of risks and benefits, protecting confidentiality and privacy, obtaining the informed consent of participants; submitting proposed studies for ethical review; maintaining public trust; adhering to the highest scientific standards; involving community representatives in research; avoiding conflicts of interest and partiality; reporting results; respecting cultural diversity [17].

Alongside the codes and guidelines there are legal documents that list criteria for use as practical reference points, including, for instance, the US Model State Public Health Privacy Act [18] and the later Turning Point Model State Public Health Act [19]. The Model Acts were developed over several years during which public health practitioners, national public health organisations and representatives from the public and private sectors at federal, state and local levels were all consulted. The criteria listed in the Model Acts are rooted in the principles of beneficence, respect for persons and justice that are typical of bioethics in general and of North American bioethics in particular [20]. Among the reference criteria listed in the Acts for public health initiatives (including surveillance activities) are:

- Public health purpose. The exercise of any public health authority or power should measurably further or support improving or sustaining the public’s health by accomplishing essential public health services and functions;
- Scientifically sound practices. Whenever possible, a state or local public health agency shall exercise its authorities or powers through procedures, practices, or programs that are based on modern, scientifically sound principles and evidence;
- Well-targeted intervention. A state or local public health agency shall strive to design and implement interventions that are well-targeted to accomplishing essential public health services and functions. An agency shall try to avoid using compulsory power in a manner that is over-broad (applying to more individuals than is necessary for the public’s health);
- Least restrictive alternative. A state or local public health agency shall employ the least restrictive alternative in the exercise of its authorities or powers, especially compulsory powers;
- Nondiscrimination. State and local public health agencies shall not discriminate in an unlawful manner against individuals on the basis of their race, ethnicity, nationality, religious beliefs, sex, sexual orientation, or disability status;
- Respect for dignity. State and local public health agencies shall respect the dignity of each individual under

their jurisdiction, regardless of his/her nationality, citizenship, or residency status; and

- Community involvement. Protecting the public's health requires ongoing public health education and outreach to encourage, facilitate, and promote community participation in accomplishing public health goals" [19].

Among the various documents produced by institutions involved in public health policies, the *Framework for the ethical conduct of public health initiatives* [21] is of particular interest. This document was prepared by the Ontario Agency for Health Protection and Promotion (Public Health Ontario) and is both extensive and clearly written (and thus applicable to various types of public health measures). In addition, because it highlights the competition between the collective and individual dimensions that, as we have seen, is such a crucial aspect, it is also particularly applicable to public health surveillance. The fact that Public Health Ontario paid special attention to the differences between the individual and the collective dimensions should not come as a surprise: the framework was derived from the "Tri-Council Policy Statement" [22], an instrument that is binding for all research conducted by Canadian institutions that receive funds from the three federal agencies that have adopted it. The document establishes a reference framework for the assessment of all research involving humans in the biomedical, social, anthropological, humanistic and technical fields. Again, the fact that the "Tri-Council Policy Statement" applies to such a heterogeneous range of research is indicative of the fact that the basic values to be respected remain unchanged and do not vary from one discipline to another, though the procedures for their application may indeed vary.

The Public Health Ontario framework lists ten key questions, each of which comprises specific aspects. The ten questions are:

1. What are the objectives of the initiative? How are they linked to potential improvements in public health?
2. Can the objectives be achieved using the proposed methods?
3. Who are the expected beneficiaries of the knowledge gained or other benefits?
4. What are the burdens and potential harms associated with the proposed initiative? Who bears them?
5. Are burdens and potential harms justified in light of the potential benefits to participants and/or to society?
6. Is selection of participants fair and appropriate?
7. Is individual informed consent warranted? Is it feasible? Is it appropriate? Is it sufficient?
8. Is community engagement warranted? Is it feasible? What level of engagement is appropriate?
9. What are the social justice implications of this initiative?
10. What are the potential longer-term consequences?

In common with the "Tri-Council Policy Statement" [22] from which it is derived, the framework is founded on widely shared principles cited in all the major institutional reference documents concerning bioethics (codes, declarations, recommendations, etc).

Checklists proposed by experts or working groups are also available: these contain practical questions de-

signed to verify that a planned intervention is consistent with ethical principles.

In 2001 Kass [23] proposed an "analytic tool, designed to help health professionals consider the ethics implications of proposed interventions, policy proposals, research initiatives and programs", consisting of six key questions:

1. What are the public health goals of the proposed programme?
2. How effective is the programme in achieving its stated goals?
3. What are the known or potential burdens of the programme?
4. Can burdens be minimised? Are there alternative approaches?
5. Is the programme implemented fairly?
6. How can the benefits and burdens of a programme be fairly balanced? [23].

The following year Childress, *et al.* [24] suggested another tool, according to which "regardless of the ethical theories taken as reference, the relevant moral considerations [where public health is concerned] should include":

1. producing benefits;
2. avoiding, preventing, and removing harms;
3. producing the maximal balance of benefits over harms and other costs (often called utility);
4. distributing benefits and burdens fairly (distributive justice) and ensuring public participation, including the participation of affected parties (procedural justice);
5. respecting autonomous choices and actions, including liberty of action;
6. protecting privacy and confidentiality;
7. keeping promises and commitments;
8. disclosing information as well as speaking honestly and truthfully (often grouped under transparency);
9. building and maintaining trust [24].

Another useful example is the guide "to considering the ethical issues in public health practice" by Nieburg, *et al* [25] and the suggestions put forward by Baum, *et al.* [26].

Some frameworks focus particularly on human rights. Gostin and Mann, for instance, propose a "human rights impact assessment" that comprises a series of procedures designed to "balance the public health benefits of a policy against its rights burdens" [27]:

- Step 1: Clarify the public health purpose;
- Step 2: Evaluate likely policy effectiveness (Is the screening program appropriate and accurate? Is the intervention likely to be effective? Is there a better approach?);
- Step 3: Determine whether the public health policy is well-targeted;
- Step 4: Examine each policy for possible human rights burdens;
- Step 5: Determine whether the policy is the least restrictive alternative that can achieve the public health objective;
- Step 6: If a coercive public health measure is truly the most effective, least restrictive alternative, base it on significant-risk standard;
- Step 7: If a coercive measure is truly necessary to

avert a significant risk, guarantee fair procedures to persons affected.

Specific frameworks

Of the frameworks concerned specifically with public health surveillance, the *Nine principles for assessing whether privacy is protected in a surveillance society* proposed by Pounder [28] and *A tool for ethical analysis of public health surveillance plans* by the Canadian Institute of Health Research [29] are worth mentioning.

The nine principles proposed by Pounder [28] are:

1. justification principle: "Information relating to any legislation or policy that involves surveillance (or extension to an existing surveillance policy) is provided so an assessment can be made to ensure that the surveillance can be justified in terms of pressing social needs and measurable outcomes; this information is provided prior to the approval of legislation or policy";
2. approval principle: "Any surveillance is limited to lawful purposes defined in legislation where such legislation has been thoroughly scrutinised by a fully informed Parliament and, where appropriate, informed public debate has taken place";
3. separation principle: "Procedures which authorise or legitimise a surveillance activity are separate from procedures related to the actual surveillance itself; the more invasive the surveillance, the wider the degree of separation";
4. adherence principle: "Procedures which authorise a surveillance activity are professionally managed and audited; staff involved in a surveillance activity are fully trained to follow relevant procedures and that such training is assessed if appropriate; any malfeasance in relation to a surveillance activity can be identified and individuals concerned suitably punished";
5. reporting principle: "A regulator shall determine what records, including statistical records, are retained and maintained concerning a surveillance activity, in order to ensure transparency and accountability to the Regulator, to the public and to Parliament";
6. independent supervision principle: "The system of supervision for a surveillance activity is independent of Government, well financed, and has effective powers of investigation and can delve into operational matters";
7. privacy principle: "Individuals should be granted a right to privacy of personal data which can be enforced by the Data Protection Commissioner and should possess a much simpler right to object to the processing of personal data in appropriate circumstances";
8. compensation principle: "An individual should obtain compensation if a surveillance activity has caused damage, distress or detriment that proves to be unjustified";
9. unacceptability principle: "If the other principles cannot be complied with in relation to a surveillance activity then within a reasonable time:
 - a) the activity ceases; or
 - b) alternative steps are taken to bring the activity into conformity with the principles; or
 - c) Parliament or a Parliamentary Committee approves the non-compliance with the relevant principle".

The Canadian Institutes of Health Research proposed *A tool for ethical analysis of public health surveil-*

lance plans [29]. This comprises eleven criteria: proportionality, usefulness, transparency, representativeness, equity, participation, independence, stigmatisation, privacy, informed consent, understandability. The checklist is illustrated in Table 1.

COMMON FEATURES

Despite their differences, all the documents cited above refer to values that are typical of public health [4, 30, 31]. These include, in particular an obligation: to improve the public's health, to promote social justice, to produce benefits, to remove harms, to distribute burdens and benefits, to keep commitments, to disclose information truthfully, to respond to suffering. These are accompanied by the obligation to ensure: equity, proportionality (which requires that any restriction to liberty not exceed what is necessary to address the needs of the community), reciprocity (or the obligation to support those who face a disproportionate burden in responding to public health measures), solidarity (which requires liaison among public and private systems to meet public health goals), stewardship (or the obligation to govern scarce resources so as to maximise the benefits and minimise collateral damage), trust between communities and public health professionals, evidence-based actions, justice, accountability of costs and efficiencies, political feasibility, the protection of individuals in the community (e.g. through the right to non-interference, participation of community representatives, respect for autonomy and the protection of confidentiality).

So far as public health surveillance is concerned, one of the problems most frequently mentioned concerns the management of personal information.

The importance of this issue is evidenced by the fact that the paragraph entitled *Ethical and legal aspects of surveillance* in the brief entry for "Surveillance of disease: Overview" in the *International encyclopedia of public health* devotes more space to this than to other public health surveillance issues. The entry affirms that: "Surveillance activities often involve surveillance workers handling communities, people, and institutions in terms of health hazard investigation, collection of technical as well as originally private information, and publication of the collected information. It is important that the purpose of surveillance should be known or fully explained as needed to the community or individuals so that the surveillance teams can obtain needed information with good cooperation on the part of the community or individuals. When it is planned, surveillance should ensure that individuals' and agencies' right to privacy will not be violated. In some cases, however, this is not simple, because the right to privacy and the right to know scientific information conflict" [32].

These frameworks highlight the requirement that data collected for surveillance purposes should be acquired, stored, used and disseminated only for legitimate ends. The following are some of the practical suggestions that can be derived either directly or indirectly from the various frameworks:

- the collection of data is legitimated in ethical terms if the data are gathered for legitimate public health pur-

Table 1
“A tool for ethical analysis of public health surveillance plans” according to the Canadian Institutes of Health Research [29]

Proportionality	Proportionality refers to the idea that the drawbacks of implementing a particular surveillance plan (such as problems related to privacy or to participation in a survey) must be offset by its benefits, which it is hoped will be greater. One of the primary justifications for surveillance is that it informs decision-making about public health programmes and activities. But this effect is hard to measure. Also, the number of subjects of surveillance and surveillance indicators continues to grow, which makes the problem of proportionality ever greater.
Usefulness	The question of usefulness has been addressed implicitly above. The ultimate usefulness of a surveillance plan is the contribution that it makes to public health. The decisions made regarding surveillance plans must therefore have this potential to improve public health.
Transparency	Transparency is the attribute that a surveillance plan has when its purposes are explicit.
Representativeness	A surveillance plan that is representative is one in which a) the phenomena to be placed under surveillance accurately reflect the health determinants and health problems that are recognised as important, and b) the populations studied are represented equitably.
Equity	While representativeness refers to the extent to which a surveillance plan allows all of the sub-groups in a population to be depicted accurately, equity refers to the need to devote particular attention to certain of these sub-groups, because certain health problems affect them disproportionately; in other words, the burden of disease is greater among them.
Participation	Participation, by partners at least, if not by the public, is assuming growing importance in the field of public health. As regards public health surveillance in particular, openness to having partners help develop surveillance plans is nothing new. It helps to ensure that the data gathered will be more relevant and will be put to better use. The advantages of having the public or certain sub-groups within the public participate seem less clear. In some cases, such participation would enable some important health concerns to be highlighted. It might also help to prevent some cases of stigmatisation by gauging the sensitivity of the chosen indicators, especially when the data are disseminated.
Independence	The increased presence of players external to the health system who have the financial capacity to take action on certain problems can place pressure on the public health authorities who develop surveillance plans to include subjects and indicators whose importance may not really have been demonstrated. Special care is advisable in such situations.
Stigmatisation	Some indicators, when cross-referenced with social and demographic data that identify certain vulnerable sub-groups of the population and that are available for fairly small geographic units, may contribute to the stigmatisation of these sub-groups by reinforcing certain prejudices.
Privacy	Privacy is the fundamental concern of surveillance authorities not to disclose information that could be used to identify individuals, households, or communities, depending on the kinds of characteristics on which data are being disseminated.
Informed consent	Medical administrative data are usually anonymised before being put to secondary use for surveillance purposes. But this is not always the case, particularly in projects attempting to monitor problems of comorbidity and multimorbidity. In such cases, consent to secondary use of data might pose problems, because it might not be possible to give this consent at the time that the data are collected.
Understandability	Lastly, the data should be disseminated in such a way that they can be understood by the public, because of course it is with the public's health that these data deal.

poses and if there is a reasonable chance that the objectives will be achieved, bearing in mind current regulations and the available resources;

- the collection, storage, use and dissemination of unidentifiable data poses fewer problems than the collection of identifiable data, and should therefore be preferred where it does not jeopardise the achievement of the proposed objectives. For the same reason any data gathered should be limited to the minimum necessary to attain the intended goal: no unnecessary data should be acquired;
- the storage of collected data, in a physically and technologically safe environment, should not be prolonged more than necessary. A supervisor should be in charge of the archive and clear rules for access laid down;
- when possible, data should be communicated in ag-

gregate form. Any dissemination of data should, obviously, comply with current regulations and have the consent of the interested parties, except where public health requirements call for the transfer of data to the health authorities;

- proper communication with all subjects involved should be maintained throughout all phases of surveillance operations. The highest possible level of engagement should be established with subjects.

All of the above confirms the already mentioned similarity between the tools for assessing the ethical compliance of public health initiatives and those for the ethical assessment of clinical research.

These similarities in turn confirm the broad agreement between the criteria governing current practice

and those governing research [33]. They also reveal the agreement between clinical ethics and public health ethics [34]. It would thus be preferable to use the expression “ethics in public health” rather than “public health ethics”: there is no specific package of ethical requirements: rather, there are general values that should

be applied – albeit with the appropriate adjustments – to the public health setting and, more specifically, to public health surveillance.

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REFERENCES

1. Institute of Medicine, Committee for the Study of the Future of Public Health. *The future of public health*. Washington: National Academies Press; 1988.
2. World Health Organization. *Revision of the International Health Regulations*. Fifty-eighth World Health Assembly. Document WHA58.3. Geneva: WHO; 2005. Available from: www.who.int/gb/ebwha/pdf_files/WHA58/A58_4-en.pdf.
3. Lee LM, Heiligh CM, White A. Ethical justification for conducting public health surveillance without patient consent. *Am J Public Health* 2012;102(1):38-44.
4. Lee LM, Teutsch SM, Thacker SB, St. Louis ME (Eds). *Principles and practice of public health surveillance*. New York: Oxford University Press; 2010.
5. Beauchamp D, Steinbock B, Preface. In: Beauchamp D, Steinbock B (Eds). *New ethics for public health*. New York: Oxford University Press; 1999. p. i-ix.
6. Bayer R, Fairchild ALR. The genesis of public health ethics. *Bioethics* 2004;18(6):473-92.
7. Petrini C. Person: centre both of clinical ethics and of public health ethics. *Ann Ist Super Sanità* 2012;48(1):1-4.
8. Lyon D. Utilitarianism. In: Becker L, Becker C (Eds). *Encyclopedia of ethics*. New York: Routledge – Taylor & Francis; 2001. Vol. 3, p. 1737-4.
9. O'Neill O. Kantian ethics. In: Craig E (Ed.). *The shorter Routledge encyclopedia of philosophy*. London: Routledge; 2005. p. 507-11.
10. Temkin LS. Equality of opportunity. In: Lafolette H (Ed.). *The international encyclopedia of ethics*. Chichester: Wiley-Blackwell; 2013. Vol. 3, p. 1701-8.
11. Kumar R. Contractualism. In: Lafolette H (Ed.). *The international encyclopedia of ethics*. Chichester: Wiley-Blackwell; 2013. Vol. 3, p. 1095-104.
12. Hicks SRC. Individualism. In: Roth JK (Ed.). *International encyclopedia of ethics*. London and Chicago: Fitzroy Deaborn Publisher; 1995. p. 432-3.
13. Petrini C, Gainotti S, Requena P. Personalism for public health ethics. *Ann Ist Super Sanità* 2010;46(2):204-9.
14. American Public Health Association. *Principles of the ethical practice of public health*. Washington: APHA; 2000. Available from: www.apha.org/nr/rdonlyres/1ced3cea-287e-4185-9cbd-bd405fc60856/0/ethicsbrochure.pdf.
15. Public Health Leadership Society. *Principles of the ethical practice of public health*. New Orleans: Public Health Leadership Society; 2002. Available from: <http://209.9.235.208/CMSuploads/PHLSethicsbrochure-40103.pdf>.
16. Tessier S, Andréys JB, Ribeiro MA. *Santé publique, santé communautaire*. Paris: Maloine; 2004.
17. American College of Epidemiology. American College of Epidemiology Ethics Guidelines. *Ann Epidemiol* 2000;10(8):487-97.
18. Gostin LO, Hodge JG. *Model State Public Health Privacy Act*. 1 October 1999. Available from: www.publichealthlaw.net/Resources/ResourcesPDFs/modelprivact.pdf.
19. The Turning Point Programme. *Turning Point Model State Public Health Act. A Tool for Assessing Public Health Laws Presented by the Public Health Statute Modernization National Excellence Collaborative*. 2003. Available from: www.turningpointprogram.org/Pages/pdfs/statute_modelphsm_TP_model_state_ph_act.pdf.
20. Beauchamp TL, Childress JF. *Principles of biomedical ethics*. 7th ed. New York: Oxford University Press; 2013. 1st ed. 1979.
21. Ontario Agency for Health Protection and Promotion (Public Health Ontario). *A framework for the ethical conduct of public health initiatives*. Ontario: 2012. Available from: www.publichealthontario.ca/en/eRepository/PHO%20Framework%20for%20Ethical%20Conduct%20of%20Public%20Health%20Initiatives%20April%202012.pdf.
22. Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, Social Sciences and Humanities Research Council of Canada. *Tri-Council Policy Statement: Ethical conduct for research involving humans*. 2nd ed. Ottawa, Canada: Her Majesty the Queen in Right of Canada; 2010.
23. Kass NE. An ethics framework for public health. *Am J Public Health* 2001;91(11):1776-82.
24. Childress JF, Faden RR, Gaare RD, Gostin LO, Kahn J, Bonnie RJ, Kass NE, Mastroianni AC, Moreno JD, Nieburg P. Public health ethics: mapping the terrain. *J Law Med Ethics* 2002;30(2):170-8.
25. Nieburg P, Gaare R, Bonnie R. Ethics and practice of public health. In: Goodman R, Rothstein N, Hoffman R, Lopez W, Matthews G (Eds). *Law in public health practice*. Oxford and New York: Oxford University Press; 2003. p. 43-62.
26. Baum NM, Gollust SE, Goold SD, Jacobson PD. Looking ahead: addressing ethical challenges in public health practice. *J Law Med Ethics* 2007;35:657-67.
27. Gostin L, Mann J. Toward the development of a human rights impact assessment for the formulation and evaluation of public health policies. In: Mann JM, Gruskin S, Grodin MA, Annas G (Eds). *Health and human rights. A reader*. New York: Routledge; 1999. p. 54-71.
28. Pounder CNM. Nine principles for assessing whether privacy is protected in a surveillance society. *Identity Inform Soc* 2008;1(1):1-22.
29. Déry M, Filiatrault F, Laporte I. A tool for ethical analysis of public health surveillance plans. In: Canadian Institutes of Health Research – Institute of Population and Public Health. *Population and public health ethics: cases from research, policy, and practice*. Toronto: University of Toronto Joint Centre for Bioethics; 2012. p. 52-7.
30. Upshur RE. Principles for the justification of public health intervention. *Can J Public Health* 2002;93(2):101-10.
31. Thompson AK, Faith K, Gibson JL, Upshur RE. Pandemic influenza preparedness: an ethical framework to guide decision-making. *BMC Med Ethics* 2006;7:E12.

32. Arita I, Nakane M, Nakano T. Surveillance and disease: Overview. In: Heggenhougen HK, Quah SR (Eds). *International encyclopedia of public health*. Oxford: Elsevier-Academic Press; 2008. Vol. 6, p. 275-89.
33. Heilig CM, Sweeney P. Ethics in public health surveillance. In: Lee LM, Teutsch SM, Thacker SB, St. Louis ME (Eds). *Principles and practice of public health surveillance*. Oxford: Oxford University Press; 2010. p. 198-216.
34. Massé R. Éthique et santé publique. Enjeux, valeurs et normativité. Saint-Nicolas, Québec: Les Presse de l'Université Laval; 2003.