

# Ethics in public health surveillance

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## Abstract

Public health programmes pose some very important ethical problems. One of the most pressing is the possible conflict between individual interests (and rights) and collective interests, which becomes particularly important in the public health surveillance setting. The present article first looks at the definitions of “public health surveillance” in a historical context and then identifies the key ethical problems that are raised. These reveal the differences – and sometimes deviations – between the bioethical issues typically encountered in a clinical setting and those that prevail in a public health context. Human rights are suggested as a possible common ground between the two. The article then draws on the specialised literature to indicate tools and checklists to help evaluate the ethical acceptability of public health surveillance programmes. It concludes with a description of the key criteria underlying these tools and checklists.

## Key words

- autonomy
- bioethics
- informed consent
- public health surveillance

## HISTORICAL NOTES AND DEFINITIONS

The history of public health surveillance can be traced back as far as the Renaissance, confirming that its importance was recognised long before recent discoveries in the field of infectious diseases and the elaboration of the diagnostic tools available to today's epidemiologists [1].

In 1938 William Farr convincingly described the importance of public health surveillance with the help of registers: “Half the life is passed in infancy, sickness and dependent helplessness. In exhibiting the high mortality, the diseases by which it is occasioned and the exciting causes of disease, the abstracts of the Registers will prove that while a part of the sickness is inevitable and part may be expected to disappear by progressive social amelioration a considerable proportion may be suppressed by the general adoption of hygienic measures (...). Morbidity registration will be an invaluable contribution to therapeutics, as well as to hygiene, for it will enable the therapeutists to determine the duration and fatality of all forms of disease (...). Illusion will be dispelled, quackery (...) suppressed, a science of therapeutics created, suffering diminished, life shielded from many dangers” [2].

Around the middle of the last century, when infectious diseases were the most pressing problem for public health authorities worldwide, Alexander Langmuir of the Centers for Disease Control and Prevention (CDC) drew up a programme for the systematic surveillance of infectious diseases. In 1963 he defined surveillance as “the continued watchfulness over the distribution and trends of incidence through the systematic collection, consolidation and evaluation of morbidity and mortality reports and other relevant data. Intrinsic in the concept is the regular

dissemination of the basic data and interpretations to all who have contributed and to all others who need to know” [3]. The basic elements underlying the notion of “surveillance” proposed by Langmuir [3] and later re-elaborated [4] are: 1) systematic and active collection of pertinent data on target disease(s); 2) assessment and practical reporting of these data, and 3) the timely dissemination of reports to individuals responsible for the formulation of action plans.

A few years later Karel Raska of the Communicable Disease Division at the World Health Organisation (WHO) extended Langmuir's definition to include epidemiological research in surveillance activities [5].

Half a century later the debate as to where the boundaries of public health surveillance should be drawn is still unresolved: “In the area of public health practice, we may need to rethink the boundary of surveillance systems. It may be wise not to expand it to a broad investigation or epidemiological research, which certainly interests many researchers or health officers but does not lead to practical public health action to reduce immediate hazard or risk. Thus, the surveillance tool as a public health action may be further refined and solidified” [6].

One particularly prickly question that continues to defy agreement concerns the boundaries between surveillance and research. Langmuir cautioned that “the actual performance of the research study should be recognised as a function separate from surveillance” [3]. Stephen Thacker, an epidemiologist with the CDC, further pursued the question, pointing to the ambiguity inherent in the definitions of “disease surveillance” and “epidemiologic surveillance”, proposing that the expression “public health surveillance” should be adopted to distinguish it from “epidemiologic research” [7].

The definition of “public health surveillance” adopted by the WHO in its Resolution WHA58.3 clearly favours Thacker’s proposal and makes an explicit distinction between public health surveillance and research activities: “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” [8].

This is not the place to compare and contrast different notions of surveillance. From the ethical point of view, however, it should be noted that:

- 1) generally leads to the adoption of control measures and public health programmes;
- 2) the boundaries between surveillance, research and control measures are frequently blurred;
- 3) surveillance programmes comprise more than the mere collection of data;
- 4) surveillance the approach introduced by Langmuir and later considerably developed marks the passage from a notion of surveillance that is restricted to individuals (*i.e.* typically contacts who had to be followed up for signs of disease without restricting their movements by isolation or quarantine) to a more modern view of surveillance concerned with diseases.

#### **THE ETHICAL PROBLEMS POSED BY PUBLIC HEALTH SURVEILLANCE: INDIVIDUAL INTERESTS VERSUS COLLECTIVE INTERESTS**

The first two of the above points may have strong ethical implications. The *International Encyclopedia of Public Health* notes first that “a surveillance system, in principle, does not include the control measures within its system” and then states that: “A surveillance system is better if it is independent from the control system, because experience has shown that on some occasions, disease prevalence was artificially modified by individuals who were responsible for control measures and sought to gain seemingly better results than what was actually occurring” [6]. This aspect will be addressed below, in the section that indicates checklists to assess the ethical acceptability of public health surveillance programmes.

The fourth point listed above refers to one of the major ethical problems encountered by public health: the potential conflict between individual and collective interests.

The significance of this issue is attested by the fact that the entry for “Surveillance of disease: overview” in the *International Encyclopedia of Public Health* contains a paragraph headed “Ethical and legal aspects of surveillance” that, while brief, is dedicated chiefly to this issue rather than to other aspects of public health surveillance: “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” [6].

The possible conflict between individual and collective interests raises questions concerning the contrast between clinical ethics and public health ethics.

#### **Clinical ethics and public health ethics: an evident contrast**

Until recently the centuries-old tradition of medical ethics handed down from Hippocrates revolved mainly around the physician-patient relationship, in other words around a relationship between individuals.

The notion of public health calls for an extension of this relationship to include the community at large. As Cicero put it: *Ollis salus populi suprema lex esto* (Let the good of the people be the supreme law) [9].

The transition from an individual to a collective approach calls for a reflection on the ethical principles involved. Can the criteria typically applied in medical ethics also be considered valid for public health ethics?

Some authors claim that there is a profound divergence between public health ethics and clinical ethics: “There is, I suggest, a sharp difference between the ethics which govern public health compared with those appropriate for clinical specialties” [10] and “The ethos of public health and that of civil liberties are radically distinct” [11].

Others maintain that traditional clinical bioethics are not only different from public health ethics, but that they are inapplicable when addressing issues of public health: “It is thus bioethics cannot serve as a basis for thinking about the balances required in the defence of public health. As we commence the process of shaping an ethics of public health, it is clear that bioethics is the wrong place to start” [12].

There is no doubt that frequently “public health and civil liberties (are) in conflict” [13]. Considerations of public health may necessitate the infringement of individual rights in order to promote collective interests, thereby posing a direct challenge to the criteria that are typically applied in clinical ethics. We must therefore ask “What are the justifications for limiting individual liberty in order to promote the public’s health as a common good?” [14].

The question is especially pertinent in public health surveillance, where it is often not practicable to ask for or receive valid informed consent. “Public health surveillance by necessity occurs without explicit patient consent” [15], and informed consent is the highest expression of the principle of autonomy [16]: to violate this requirement is to undermine the very foundations of bioethics.

A solution to all these questions could perhaps be found by referring to a context that has historically been especially afflicted by such problems: surveil-

lance in the early years of the AIDS epidemic: “In contemporary public health, no condition has pushed us to think about how individual rights relate to public health more than HIV/AIDS” [15]. This wake-up call was partly triggered by the fact that the emergence of AIDS in the 1980s coincided with the spread of increasing awareness of and sensitivity to the issues surrounding the protection of personal data and the autonomy of individual decisions in the contexts of clinical medicine and public health [17]. The enormity of the ethical dilemmas posed by AIDS surveillance induced the United Nations to consider the implications, and a special consultation led to the adoption of the *International Guidelines. HIV/AIDS and Human Rights* [18], subsequently updated [19]. This document states categorically that “Public health interests do not conflict with human rights” [18].

Human rights may thus provide a common ground between individual and collective interests – and also, therefore, between clinical bioethics and public health ethics. Seen in this light, the conflict between bioethics and public health ethics is perhaps simplistic.

### ***Human rights as a common ground for bioethics and public health ethics***

MK Wynia is one of the authors to highlight the simplistic nature of the contrast between bioethics and public health ethics and how human rights are a fertile common ground: “According to the *oversimplified* view public health ethics is based entirely on a particular type of consequentialism; let’s call it “health utilitarianism”. That is, the proper goal of public-health efforts is to advance the health of as many people as much as possible. Correct actions in public health can be determined by calculating the net health benefits to be gained by an action. If true, this would imply that individual rights can matter to public-health ethics only insofar as they affect health outcomes (...). But the conflicts that arise when attempting to actually implement this oversimplified version of public health ethics are stark reminders of its inadequacy for practice (...). (T)here is *strong evidence that attention to human rights is critical to good community health, as well as individual health*” (author’s italics) [20].

In bioethics, as in public health ethics, attention to human rights leads to further reflection in a historical perspective. When Van Rensselaer Potter coined the term “bioethics” [21, 22] there was still a marked tendency among medical ethicists to adopt a paternalistic stance on the subject. When viewed within the framework of the noted principles of North American bioethics initially proposed for trials with human subjects [23] and later extended to every field of medical ethics [24], this tendency reveals a certain bias towards the principle of beneficence. Around the 1980s a widespread movement to restore the centrality of individual rights led to emphasis on the principle of autonomy. Today there is increased sensitivity to the issues of equity in health, negotiation in decision-making and wider participation that may point to a gradual shift towards the principle of justice. Against this background the issue of ethics in public health certainly has a place.

### **ETHICAL MODELS FOR PUBLIC HEALTH**

The issues of ethics in public health can be approached from various angles. One of the most popular is *utilitarianism* [25]. The utilitarian doctrine holds that the proper course of action is one that produces the greatest well-being and least suffering for the greatest number of people [26]. The consequences of actions are assessed on a cost/benefit basis, making this a typically consequentialist approach [27].

Some of the major criticisms of utilitarianism are that: it is inherently unfair, since although the overall good is considered, its distribution is not; not all good can be quantified; there is a risk that the cost/benefit analysis is based on a comparison between non-homogeneous values; good intentions do not make an inherently wrong action either good or just (in other words, a good outcome could be achieved through a bad action, which is morally unacceptable). Attempts have been made to address these flaws by gradually moving away from the “hard utilitarianism” proposed by Jeremy Bentham (1748-1832) [28] and John Stuart Mill (1806-1873) [29] towards forms of “soft utilitarianism” that seek to incorporate new criteria such as: respect for individuals, equity, impartiality, neutrality. However, these criteria cannot easily compensate for the intrinsic weaknesses of the utilitarian approach.

*Deontologism* favours a contrasting stance [30] that adopts a typically Kantian view of ethics [31] based on universal moral values and the noted Kantian imperative: “Act in such a way that you treat humanity (...) as an end and never merely as a means to an end” [32].

One of the major criticisms of this approach is the fact that it underestimates the consequences of acts: moral acts may have harmful outcomes.

*Communitarianism* holds that we must reject the notion of unvarying universal truths [33]. It differs radically from deontologism [34], asserting that morality is a cultural value born of a community’s traditions [35]. Communities are not seen merely as collections of juxtaposed individuals but as groups of people who share values, customs, institutions and interests [36].

The major criticisms directed at this view are its rejection of values that are common to the whole community and the risk that it give rise to a “tyranny of the majority”, when minority groups are also present in a community.

*Egalitarianism* considers equality to be one of humankind’s fundamental values. One of the authors who has contributed to analysis of this trend in recent decades is John Rawls [37, 38], for whom “Justice is the first virtue of social institutions, as truth is of systems of thought” [39]. Egalitarianism holds that every individual should have equal rights and equal opportunities, regardless of his or her condition [40], though the achievements of each may differ [41].

According to its critics, this approach risks over-emphasising the means to the detriment of the end, while also failing to make proper allowances for individual and social peculiarities.

*Liberalism* gives priority to freedom and autonomy [42, 43], holding that public authorities should do no

more than protect individual rights, without interfering with free enterprise, and that the State should remain neutral [44].

Its critics highlight the fact that in some sectors, including public health, market rules alone are inadequate or insufficient.

*Contractualism* asserts that right decisions are based on correct procedures and the involvement of all the parties in decision-making [45]. Emphasis is therefore placed neither on the motivations nor on the consequences of actions, but on their formal correctness: decision-making procedures, in other words, should be regulated *a priori* and rules should be observed [46].

This approach has drawn criticism on several grounds. In the first place, by considering only the rules it neglects the fact that some human values should be respected regardless (one could use contractual reasoning to justify crimes and infringements of human rights). Additionally, decisions whose validity is based only on the correctness of the negotiation procedures would exclude all those who for varying reasons are not able to take part in the negotiations.

*Individualism* maintains that morals cannot be founded on facts, or on objective or transcendental values, but only on the autonomous decisions of the individual. It is thus a form of non-cognitivism, since it holds that values cannot be known. Anything that is free of constraint is thus allowed, provided it does not impair the freedom of others [47].

Critics argue that the kind of freedom proposed by individualism is partial, since not everybody is able to express it. With its emphasis on the principle of tolerance and the absence of relevant harm it risks justifying the survival of the fittest.

*Personalism* places the person above all else [48], while differing radically from individualism, since it considers the person as belonging to humankind. According to the personalists, the common good is constructed by promoting and valuing the good of individuals. Seen in this light, the noted principles of North American bioethics (beneficence, autonomy justice) can be re-proposed as: the therapeutic principle (care of the person); freedom linked to responsibility, sociality-solidarity [49].

The critics of personalism point to the differences between its various forms (ontological, hermeneutic, relational, etc.).

*Table 1* offers a brief summary of the ethical requisites that each "ism" demands of public health interventions.

## CODES AND CHECKLISTS FOR ETHICS IN PUBLIC HEALTH SURVEILLANCE

Of the several codes of public health ethics that have been published, the one adopted by the American Public Health Association is one of the better known [50]. This and other similar codes of ethics are a useful guide for the specific case of public health surveillance.

Several experts have, either individually or in groups, drawn up checklists or guidelines to assess the ethical acceptability of public health surveillance programmes, as have numerous institutions. Most of these checklists take a pragmatic approach and are formulated as operational tools.

Most dedicate ample space to the problem of data protection and confidentiality. The present article will instead focus more on other aspects, as the protection of privacy in the public health setting is already the subject of a large body of literature [51, 52].

Some of these checklists are summarised below, or as *Tables*.

Pounder proposed "Nine principles for assessing whether privacy is protected in a surveillance society" [53]: these are shown in *Table 2*.

The Canadian Institutes of Health Research proposed "A tool for ethical analysis of public health surveillance plans". This comprises eleven criteria: proportionality, usefulness, transparency, representativeness, equity, participation, independence, stigmatisation, privacy, informed consent, understandability [54]: they are described in *Table 3*.

Other checklists have been proposed which, while concerning public health ethics in general rather than surveillance in particular, are eminently adaptable to assess public health surveillance programmes.

Childress *et al.* suggested that "Regardless of the ethical theories taken as reference, the relevant moral considerations 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;

**Table 1**  
Public health ethics in different cultural models

Public health interventions are ethical if they promote	
Well-being through scientifically calculated measures	<b>Utilitarianism</b>
A good and virtuous life in a just society	<b>Deontologism</b>
Attitudes of brotherhood among members of communities	<b>Communitarianism</b>
Equality and fairness among persons of different social backgrounds	<b>Egalitarianism</b>
Freedom from disease and premature death	<b>Liberalism</b>
Individual freedom and autonomy	<b>Individualism</b>
The common good, through the good of the individual, while fostering solidarity	<b>Personalism</b>

8. disclosing information as well as speaking honestly and truthfully (often grouped under transparency);
9. building and maintaining trust" [55].

Another suggestion was offered by Krass, who proposed a six-step model for public health:

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? [56].

## CONCLUSIONS

The ethical problems posed by public health surveillance have been specifically addressed in numerous studies in the past, and various factors have led to an increase in this interest in recent years, including the diffusion of new and unforeseen epidemics and a greater awareness of and sensitivity towards the issues involved [57].

The checklists shown above can help to assess the compatibility of public health surveillance programmes with ethical principles. One of the major problems highlighted by these tools is the fact that, given the

virtual impossibility of obtaining informed consent, programmes for public health surveillance frequently necessitate an infringement of the principle of autonomy. Today it is widely accepted that "Overriding individual autonomy must be justified in terms of the obligation of public health to improve population health, reduce inequities, attend to the health of vulnerable and systematically disadvantaged persons, and prevent harm. In addition, data elements collected without consent must represent the minimal necessary interference, lead to effective public health action, and be maintained securely" [15].

Returning to Childress and co-authors, they suggest five useful "conditions intended to help determine whether promoting public health warrants overriding such values as individual liberty or justice in particular cases". These conditions encapsulate the key criteria referred to in the various checklists. They are: effectiveness; proportionality; necessity; least infringement; public justification" [55].

In summarising the criteria listed above it may also be helpful to refer to a proposal formulated by the noted biolaw expert Lawrence Gostin on the spread of Severe Acute Respiratory Syndrome (SARS). His concise proposal makes a suitable and practical conclusion: "Coercive measures, which violate individual rights, are acceptable when:

- the risk to public health is demonstrable;

**Table 2**

Nine principles for assessing whether privacy is protected in a surveillance society (from Pounder [53])

<b>Principle 1</b>	<b><i>Justification principle</i></b>	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.
<b>Principle 2</b>	<b><i>Approval principle</i></b>	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.
<b>Principle 3</b>	<b><i>Separation principle</i></b>	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.
<b>Principle 4</b>	<b><i>Adherence principle</i></b>	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.
<b>Principle 5</b>	<b><i>Reporting principle</i></b>	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.
<b>Principle 6</b>	<b><i>Independent supervision principle</i></b>	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.
<b>Principle 7</b>	<b><i>Privacy principle</i></b>	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.
<b>Principle 8</b>	<b><i>Compensation principle</i></b>	An individual should obtain compensation if a surveillance activity has caused damage, distress or detriment that proves to be unjustified.
<b>Principle 9</b>	<b><i>Unacceptability principle</i></b>	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.

**Table 3**

"A tool for ethical analysis of public health surveillance plans" according to the Canadian Institutes of Health Research [54]

<b>Proportionality</b>	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.
<b>Usefulness</b>	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.
<b>Transparency</b>	Transparency is the attribute that a surveillance plan has when its purposes are explicit.
<b>Representativeness</b>	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.
<b>Equity</b>	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.
<b>Participation</b>	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.
<b>Independence</b>	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.
<b>Stigmatisation</b>	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.
<b>Privacy</b>	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.
<b>Informed consent</b>	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.
<b>Understandability</b>	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.

- the intervention is likely to be effective, cost-effective, not overly invasive, fairly distributed;
- the process for pursuing intervention is just and publicly transparent" [58].

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