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Summary of ethical concerns
raised in the surveillance plans
reviewed by the Comité
d'éthique de santé publique
between 2003 and 2012

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Comité d'éthique de santé publique

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AUTHOR

Comité d'éthique de santé publique

EDITORS

Lynda Bouthillier
General secretariat, communications and documentation division

Michel Désy
General secretariat, communications and documentation division

France Filiatrault (coordination)
General secretariat, communications and documentation division

LAYOUT

Royse Henderson
General secretariat, communications and documentation division

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1 INTRODUCTION

In 2013, after 10 years of existence, the Comité d'éthique de santé publique [Public Health Ethics Committee] (CESP) felt compelled to review the experience that it had developed with regard to its specific mandate to provide ethical reviews of surveillance plans. This document summarizes all the ethical concerns identified by the Committee through the review of the different surveillance plans that were submitted to it between the time of its establishment and 2012. This summary of the opinions allows the Committee to cast a broader critical look on the ethical reflection surrounding the practice of ongoing surveillance of the population's health status and its determinants. Our hope is that this document represents an original contribution concerning the ethical aspects of public health surveillance in Québec.

1.1 CONTEXT AND OBJECTIVES

Since its adoption in 2001, the *Loi sur la santé publique*¹ [Québec Public Health Act] (LSP) (CQLR c. S-2.2) formally recognizes surveillance as an essential public health function. In doing so, the Act requires that the minister and public health directors prepare surveillance plans, for their respective purposes, and that these plans be submitted to the CESP for review (Art. 35). Indeed, the mandates of the CESP include reviewing draft surveillance plans and social and health surveys for surveillance purposes (*Loi sur l'Institut national de santé publique du Québec*² (CQLR c. I-13.1.1), Art. 19.2 and 19.3).

This document responds to the desire of the CESP, firstly, to take stock of its own practices, as well as to propose the basis for an in-depth ethical reflection on the subject of surveillance. Let us note that public health ethics applied to surveillance is a relatively recent field of expertise. Such reflection was, just a few years ago, still uncommon.

Ethical reflection on surveillance could not take place without the contribution of the actual parties active in this field, be it to inform the various activities in this area or to steer, on occasion, the Committee toward possible ethical concerns raised by the practice. Since these people are on the frontlines and are asked to integrate an ethical perspective into their work, this document is likewise addressed to them. The Committee conceived this report as a reference tool that presents a body of ethical concerns, so that readers may remain aware of this dimension of their practice and be open to new questions that may arise.

In preparing this summary, all the opinions produced by the CESP following a review of surveillance plans were considered (section 8.1). In all, a dozen plans were thus reviewed between 2003 and 2012: five were produced at the provincial level, while the others were at the regional level. These plans were often different from one another, both in their respective scope and their presentation. The ethical concerns raised by the Committee were extracted from this corpus, whether they took the form of simple comments or, more formally, recommendations pertaining to more pointed questions (regarding a particular indicator, for instance) or broader questions (on the profusion of objects or indicators, among other

¹ http://www2.publicationsduquebec.gouv.qc.ca/dynamicSearch/telecharge.php?type=2&file=/S_2_2/S2_2.html.

² http://www2.publicationsduquebec.gouv.qc.ca/dynamicSearch/telecharge.php?type=2&file=/I_13_1_1/I13_1_1.HTM.

things). The analysis of this portrait enabled the Committee to reflect in greater depth on these ethical aspects.

1.2 OVERVIEW OF THE CONTENTS

The next chapter explains what the CESP means by the ethical review of surveillance plans. Chapter Three, which is the most detailed, presents all the ethical concerns addressed in the CESP opinions from 2003 to 2012, taking care to place them in context and, where applicable, to illustrate them using examples. Chapter Four puts the various ethical concerns into perspective, proposing they be organised according to three major themes: specificity, balance, and spaces for dialogue. The fifth chapter highlights, among all the ethical concerns, those that merit further investigation and for which additional work could be considered. Lastly, the conclusion reviews all the elements emerging from this report and presents certain perspectives on ways to integrate what was learned or push the reflection further.

2 ETHICAL REVIEW IN SURVEILLANCE

Public health ethics and surveillance ethics are relatively new areas of study and reflection largely developed since 2000. As different methods of approaching public health ethics exist (Lee et al., 2012), so too do different methods exist of addressing the ethical concerns raised in the exercise of surveillance of the population's health status.

One of the first difficulties when looking at studies related to the ethics of surveillance is that of the definition itself of the field. Most scientific articles with titles containing the terms "ethics" and "surveillance" (public health surveillance, ethics, or ethical issues) address either the long-standing discussion on the distinction between research activities and surveillance activities (Fairchild, 2003; Fairchild & Bayer, 2004; Rubel, 2012), or the issue of privacy and confidentiality, particularly in public health monitoring and research. It is important to underline that surveillance, in the United States as well as in other parts of Canada and elsewhere, encompasses public health monitoring and epidemiological research. While these different functions may share similar methods, they differ in terms of purposes and in terms of the powers held by the authorities responsible for them. These elements influence the manner in which ethical questions present themselves.

The most substantial references that we found in this body of literature are Heilig & Sweeney (2010) and Petrini (2013). Heilig and Sweeney consider that the concerns associated with the respect of privacy and confidentiality, as well as the question of the protection of personal information, remain at the heart of ethical issues in surveillance. The authors refer to the principles of bioethics (beneficence, respect for the individual, and justice) and illustrate their scope in surveillance activities. They also discuss various normative frameworks (legal, professional or administrative) that control, among other things, the acquisition, management, and dissemination of surveillance data. They emphasize in particular the responsibility of the parties concerned in ensuring that surveillance is performed in accordance with explicit, legitimate purposes, while respecting privacy and confidentiality. With regard to the work by Petrini, its goal is to offer a definition of public health surveillance and to present the major ethical issues associated with this surveillance, notably in terms of human rights. He also presents recent tools for reflecting on the ethical dimensions of surveillance, notably the one developed for the CESP (Déry et al., 2012).

As for the CESP, its practices are based on a pragmatic, reflection-based approach. This means that the CESP performs the ethical analysis of specific situations, thereby placing emphasis on the practical resolution of a problem or an ethical concern, i.e., a situation underlying a conflict or tensions between two or more values or between values and standards. The Committee's deliberations give first importance to analysing the context and the consequences for those concerned, as well as to decision-making (Parizeau, 1996: 695). Overall, the CESP's ethical review process aims to take values and standards into consideration in the formulation of a reasoned decision and the implementation of an appropriate action. In examining the surveillance plans submitted to it, the CESP thus aims to clarify the values that are raised at the various stages of development and implementation of the plan, with the objective of throwing light on possible tensions and articulating the reasoning for the choices that have to be made along the way.

Within the ethical perspective of the CESP, a surveillance plan cannot be defended only by arguments based on applicable scientific and legal standards. The argument must also highlight the values being considered priorities and, where applicable, clarify the limits of the plan to meet certain values, which conflict with the first.

Any entity generating scientific knowledge, such as that resulting from surveillance, mobilizes a process that aims for the greatest possible objectivity. However, this desired objectivity does not guarantee complete neutrality in terms of values. In effect, as Weinstock mentions, "evidence-based data does not constitute an idea exempt of values, as this data and its production is the result of human decisions. [...] The danger of considering scientific activity as neutral and free of all values is that these values may enter our practices without us realizing it" (Weinstock, 2007).

Weinstock uses the notion of decision nodes to speak of these moments when, in practice, evaluation questions present themselves that require the professional to make choices in the course of his or her activities. These questions may be social, administrative, strategic, or political in nature. The response to these questions, indeed their very formulation, is ultimately influenced by values, which is what the ethical dimension of practice refers to.

In surveillance, these decision nodes appear, among other places, in the different components and activities surrounding the development and implementation of plans. For example, when a surveillance program is being planned, a selection of objects (health problems and determinants) and health indicators must be made. However, the choices made are not independent of political and organizational issues, such as, for example, with regard to the dominance of physical health in the concerns of the health care system. These choices are not independent either of the social importance given to various health problems (CESP, 2004: 8).

How can one ensure that the different surveillance activities, as well as the very design of a plan, are explicit with regard to the values underlying them? That these activities are not influenced by a strong adherence to values that could overshadow others? How can one ensure that they do not contain, within themselves, potential negative consequences for population sub-groups and the individuals associated with these sub-groups?

The consideration of the ethical dimension of surveillance activities does not attempt to eliminate all biases in terms of values—which is impossible—but seeks to make these values explicit, and even to justify them, without which process these activities could be based on a faulty concept of the scientific and be cut off from dimensions essential to the deliberation on best practices (Fischer, 1980).

3 THE PRIMARY ETHICAL CONCERNS ADDRESSED IN THE OPINIONS

Surveillance is defined as "an ongoing process of evaluating the population's health status and its determinants through the collection, analysis, and interpretation of data on health and its determinants at the population level" (MSSS, 2007: 19). To some extent, it constitutes the cornerstone of public health, supplying the informational basis on which public health activities are organized. The surveillance mandate is thus linked to the ultimate purpose of public health, i.e., improvement of the population's health status, while aiming to reduce health-related social inequalities. The success of this mandate lies in the effective, efficient dissemination of information useful to the decision-making of public health stakeholders, partners, and the population.

The surveillance plans submitted to the CESP between 2003 and 2012 feature the different components of this process of evaluating health status. More precisely, they must specify, in accordance with the *Loi sur la santé publique*, the purpose and objects of the surveillance, the personal or non-personal information that is necessary to obtain, the information sources envisaged, and the plan of analysis of the information required to perform the function (Art. 36).

The following sub-sections present the core ethical concerns that emerged from the CESP's opinions on these surveillance plans.

3.1 SOCIAL CONTRACT AND RESPONSIBILITY

Surveillance is performed in a manner that covers a very large spectrum of health problems and of the determinants (risk and protection factors) associated with them, which suggests that multiple aspects of individuals' lives are thus observed. Indeed, the concept itself of surveillance implies a relationship of authority, of power even, between those who do the surveillance and those who are the subjects of it, a relationship that is also accompanied by responsibilities that come with the handling of an impressive quantity of data which serve to produce information that acts as a portrait of reality. This power also lies in the political-administrative status held by public health agencies that have a surveillance mandate, with the authority that is granted to them.

The tension between the risk of violating privacy and the anticipated health benefit resulting from the surveillance activities is resolved through the idea of an implicit social contract, outlined by the *Loi sur la santé publique*, in which the population accepts that the information concerning it be collected and used so that health care services and public policies can be implemented to better serve it. In return, the State undertakes to collect only the information necessary, to manage it in a secure manner, and to use it with a view to producing quality information useful to those who undertake actions intended to improve the population's health status. The success of public health activities, including surveillance, depends on the relationship of trust existing between public health stakeholders and the population that they serve. Access to this much data is, consequently, accompanied by a responsibility and an obligation to be transparent about its use.

More generally, the status of public health (and of its various functions) as an institution financed by public funds, whose role is to serve the entire population, requires that its mandate be fulfilled in a responsible manner. This responsibility is embodied not only by the professionals operating in the field of surveillance, but also, and particularly, by the institutions themselves, through their mandates and action plans. On the other hand, in reality, this responsibility is shaped by the means available to act on these various states of health or on their determinants. Yet, often, this is not possible for various reasons, such as due to a lack of resources or the absence of interventions that are recognized as effective in regard to certain problems.

Example

Within the context of the "social contract" legitimizing the collection of information for surveillance purposes, the Committee reiterates the obligation to give explicit justification for this collection within the scope of the surveillance plan, the Québec Common Surveillance Plan (*Plan commun de surveillance*, PCS), or any other plan developed by the authorities concerned and submitted to the CESP.

The Committee believes that the legislative measures concerning the surveillance function and the implementation of the PCS should, at the present time, be sufficiently assimilated so that all investigation tools that are submitted to it be understood as a source of information included in a surveillance plan in an explicit manner, thereby respecting what the Committee calls the "social contract" which legitimizes the collection, analysis, and dissemination of data for surveillance purposes (CESP, 2005b).

3.2 PURPOSES AND OPERATIONAL OBJECTIVES

A surveillance plan clarifies the exercise of this function. It presents its intentions through the purposes adopted and the operational objectives. This is to say, the manner that was selected to achieve these purposes by stating the plan's orientation, its meaning, and the intention that drove its conception. The planning process provides a global portrait of the surveillance activities, particularly in the context where plans cover a vast group of themes. A periodic return to this macro level, at least during development, allows for adjustments to be made as required, notably to ensure that the project is based on the values of transparency, impartiality, fairness, respect for people, and utility.

Determining the purposes does not consist solely of clearly formulating the broad intentions of a project; attention must also be given to the nature of these intentions and to the overlaps that a surveillance plan may have with other fields, such as research or evaluation. Problems could arise, for example, if one had the intention of achieving research goals under the cover of a surveillance project. Such confusion could undermine the population's trust in public institutions with regard to the use of data concerning it.

Furthermore, transparency requires that the purposes sought by surveillance and the manner selected to achieve them be clearly stated. This also means keeping in mind that the improvement of health—the ultimate purpose of public health—does not constitute an absolute principle justifying without reserve all public health actions, including those related

to surveillance. The end does not necessarily justify the means, particularly if we find ourselves facing a significant conflict between values.

To be able to adequately support decision-making, the *Loi sur la santé publique* has established six main operational objectives which represent as many levers for optimal surveillance of the population's health status and for the production of useful information:

- provide an overall picture of the health status of the population;
- observe trends and temporal and spatial variations;
- monitor the evolution, within the population, of certain specific health problems and their determinants;
- detect emerging problems;
- identify priority problems;
- develop prospective scenarios of the health status of the population.

Do these operational objectives, particularly the last three, not contain within themselves an ethical dimension that merits explanation? For example, the concept of emergence itself and the methods allowing for the detection of emerging problems could, in certain cases, reflect a different interpretation of situations which would frame the problematics. It might be tempting, moreover, to define a problem as emerging in order to attract attention to a particular issue—media, political, and scientific attention being more easily drawn to novelty.

The CESP also recommends that reflection be conducted on the scope of the six objectives with regard to risk assessment in the management of public health. Within this context, the assessment of health risks takes place within a forward-looking practice that aims to determine what has the greatest priority, what factors are important in making allocation decisions in order to avoid, among other things, risks of harmful effects on the population's health. Such practice could not take place without underlying assumptions, without an initial idea of what is most important, of what presents the most important value.

Lastly, looking at the project as a whole, considering the components from a comprehensive viewpoint, allows one to evaluate the utility and efficacy of the information produced, relative to the efforts made to produce it. Considering the actions performed within a context that includes other essential public health functions such as promotion, prevention, and protection, the question is this: is the balance justifiable between the human and financial resources required in surveillance for the development of objects and indicators and the utility of the information produced, i.e., its contribution to decision-making and its effectiveness (for the improvement of the population's health)?

As such, considering the impressive quantity of surveillance objects and indicators proposed, particularly in the PCS and the *Plan ministériel de surveillance multithématique* [Québec ministerial multi-thematic surveillance plan] (PMSM), the Committee recommends that reflection be given to the relationship between the efforts made in surveillance and other areas of public health. The same question can be posed with regard to other public health support functions, such as research or evaluation. Do they contribute, to the same extent as surveillance, to supporting decision-making? Are the efforts given to the development and

support of these various functions fairly distributed? Evaluating surveillance's contribution alongside other public health functions raises the question of the proper allocation of resources.

3.3 DEFINITION OF HEALTH

A surveillance plan is based on a definition of health that guides the development of a portrait of the population's health status. The challenge consists in finding a balance allowing the definition adopted to meet the needs expressed in terms of information. This is what the surveillance plan should reflect, notably through its selection of objects and indicators.

The definition itself of health can change and be influenced by different factors, including the values given priority by a particular society. The definition to which we habitually refer can be found in the *Loi sur les services de santé et les services sociaux*³ (LSSSS). According to this definition, health is no longer perceived simply as the absence of illness and social problems: instead, it means "the physical, mental, and social capacity of persons to act in their community and to carry out the roles they intend to assume in a manner which is acceptable to themselves and to the groups to which they belong" (CQLR, Chapter S-4.2, Article 1 – definition adopted in the Common Surveillance Plan- PCS, MSSS, 2004: 17).

This definition constitutes the normative starting point around which national surveillance plans are structured (PCS and PMSM). It is therefore this definition, in principle, which serves as the conceptual model for building a portrait of the population's health, while integrating not only physical dimensions, but also psychological, community, and social ones. It results from the definition and the conceptual model that a very large number of elements can be considered as health determinants, and thus become objects of surveillance. Consequently, it would be necessary, in principle, to collect a very large amount of information. That is why a clear vision of the purposes of the surveillance is necessary to allow one to respond to the following questions: would citizens find a clear, comprehensible justification in the plan for this access to this massive volume of information concerning them? What is the key that would enable citizens to grasp the nature of the plan, what it aims to do, and, by way of these, the importance of surveillance in improving the population's health?

³ http://www2.publicationsduquebec.gouv.qc.ca/dynamicSearch/telecharge.php?type=2&file=/S_4_2/S4_2.html.

Example

The CESP has noted a considerable gap between the definition of health used in the PCS reference framework and the definition that ended up being used: in fact, the presentation of the PCS appeared, at first glance, to be based on the deductive method (here is the definition of health and the conceptual model that specifies the health determinants, and here are the objects, measurements, and indicators adopted). Yet, what was said regarding the development of this surveillance plan and of the choices appeared instead to use an inductive approach (here are the objects determined in part by the National Public Health Program, here are the existing data banks that provide access to reliable information, and here, therefore, is what enables us to monitor the population's health status and its determinants) (CESP, 2004).

As work continues on the National Surveillance Plan—which will combine the PCS and PMSM—the question of the definition of health will be raised again. In the view of the CESP, and as it formulated it at the time of the PCS, initial work will consist of identifying the inevitable gap between the operational and reference definitions of health. It seems preferable to specify that the former has a more limited scope than the latter, which also influences the scope of criteria adopted to determine the objects and indicators that will be monitored. This would underscore, among other things, the constructed nature of health and, as a corollary, of the surveillance plan.

3.4 BALANCE AND REPRESENTATIVENESS OF OBJECTS AND INDICATORS

Surveillance contributes to the construction of a representation of a population's health through the development of analysis plans and the choice of objects and indicators in the plan. However, like all representations of a complex reality, the portrait thus drawn does not stand as a mirror that accurately reflects reality: the resulting image of the health status is coloured by the choices made, the objects, the indicators, and the data sources adopted. These constitute the lens through which the image of a population's health status is created. Political as much as scientific, the discussion on surveillance is also performance-based: stating the categories of determinants, for example, renders this classification operational. Now, even a categorization that is intended to be as neutral as possible will always exercise effects that are not.

Example

The Committee questioned the classification of teen pregnancy and obesity as health problems. Without calling into question the fact that these conditions are more associated with physical or psychosocial health problems, the Committee questioned the possible influence of this classification on the social representation of these situations and the persons experiencing them (CESP, 2004: 8).

The objective of a surveillance plan is to inform decisions so that they are favourable to health; this consequently requires the use of reliable measures, with recognized pertinence and utility, which adequately take into consideration the phenomena one wishes to monitor. The pertinence, consistency, and representativeness of the objects and indicators selected

are essential conditions for their proper use. Ultimately, the information that they provide will only have meaning when they are used by decision-makers, stakeholders, or the population, to enlighten and support decision-making that promotes the improvement of health. It is therefore important that, at the basis of this, the needs of these groups be well defined.

The portrait of a population's health has long been presented in terms of health problems and risk factors. However, health determinants include more positive elements that act as factors protecting the health of individuals and communities and are integrated into promotion and intervention strategies; for example: social cohesion, empowerment, and social capital. The adoption of a broader definition of health, of more encompassing conceptual models such as those inspired by Friedman, Hunter, and Parrish (2002), or of positive approaches based on factors "that create health" (Roy and O'Neill, 2012) should, at the same time, lead to ensuring that more positive determinants are also objects of surveillance.

The Committee has observed the limited development of objects and indicators relative to such determinants. The Committee therefore encourages those responsible for surveillance plans to develop and include more positive objects and indicators that are capable of representing the strengths and potential of people and communities. Research could be oriented toward the development of indicators of this nature; these could also respond to objectives of the National Public Health Plan that are less often covered by large surveillance plans in order to realize such values as justice, autonomy, solidarity, and even shared responsibility.

A contribution of this nature could lead, in the medium term, to new intervention perspectives. As Bernard Perret states: "Allowing new information elements to enter into our social representations is, in itself, preparing ourselves to judge differently. [...] Judgements depend on the information basis on which they are made, and vice-versa. [...] Choosing and prioritizing the aspects of social reality that are important to know and make known must be considered an act of judgement in its own right [...]" (Perret, 2002: 25).

Moreover, despite a significant number of objects and indicators included in surveillance plans, notably those developed at the provincial level, the CESP has observed an apparent imbalance between the various themes addressed. Clearly, mathematical calculation of the number of objects and indicators, in each of the themes, could not by itself rightly convey the internal balance of a plan.⁴ Nonetheless, it seems that certain categories appear to be underinvested; this is true for the status of mental and psychosocial health, determinants of the psychosocial environment, and indicators related to the development of communities as a health determinant. Generally, the proposed indicators instead seem to attempt to go into greater detail concerning problems already known (CESP, 2004: annex 1.1).

Could such a situation have undesirable consequences for the population? For example, does the strong representation of objects related to physical health status result in attention being focused only on health problems associated with physical health, and that these thereby become priority problems? It is true that physical health is easily "measurable"; the

⁴ The objective of "covering the theme addressed in as consistent and complete a manner as possible" (MSSS, 2008: pg. 16) could require the adoption of a number of fairly different indicators, depending on the surveillance object selected (CESP, 2010: pg. 13).

symptoms are often concrete and the problems more easily detectable thanks to biomedical technologies. As such, physical health appears to be more easily definable, unlike mental or psychosocial health, where the problems are often more difficult to assess.

These difficulties should not, however, be permanent obstacles to the inclusion of these dimensions, but should constitute areas of development that make use of more appropriate methods. The Committee has observed, in fact, that certain other themes ought to enrich the health problems that they cover by adding new dimensions. This is true, among other areas, for health surveillance in the workplace, which remains poorly documented with regard to musculoskeletal or mental health problems caused by certain ailments or disabilities, for example. The Committee has also identified other themes on which reflection is needed.

Example

In certain cases, taking the ethnocultural dimension into consideration could shed new light, with a view to detecting inequalities with regard to work-related health problems. Conversely, in other areas of surveillance, the CESP encourages those in charge to question certain automatic responses that lead to an almost systematic adoption of this variable (language spoken and place of birth). Is it always pertinent to bring this perspective in? What is its meaning within the contexts in which it is used? (CESP, 2012).

Faced with these challenges, the Committee invites those responsible to undertake a process that would lead to the identification of global choices among all the different themes, so as to ensure a distribution of objects and indicators that would permit a fair representation of the population's health status and its determinants. The criteria thus established would enable one to delineate the nature of the objects of surveillance (what belongs to a given health status, and what belongs to a determinant) as well as their "more refined" classification according to the different categories of objects (e.g., demographic conditions, lifestyles, etc.) and fields of intervention (infectious diseases, general surveillance, etc.).

When a surveillance plan is the result of collective work, as was the case for the PCS and the PMSM, there is undoubtedly a risk that it may not use a unique logic in establishing common criteria with regard to the selection and classification of surveillance objects. Undoubtedly, as well, no single angle exists from which an object can be considered; the authors of the PCS thus gave the example of health problems that, in the case of objectives in the prevention of infectious diseases, are considered risk factors (determinants) for other health problems. The CESP recommends that authors of plans take a global view, so as to strengthen its consistency and facilitate comprehension. Furthermore, this comprehensive view ensures that no preconceived ideas exist such as might, for example, prioritize a narrow categorization of "health problems" or "behaviour"; the former case could limit the responsibility of the individual in relation to his or her health, while the latter case could place all the responsibility for health on the individual (CESP, 2004).

Lastly, certain objects and indicators developed for different themes or domains of intervention can represent differing facets of a same health problem. Indeed, it sometimes happens that surveillance professionals work within teams dedicated to one specific public health problem. However, as the box below illustrates, choices made in one area can have

consequences on others. Organization of work by domain of intervention does not facilitate an integrated approach to surveillance, since it often confines the manner of approaching the same health objects or making use of identical or similar indicators. In this sense, coordination efforts between the managers of different areas of intervention would foster a more optimal use of indicators and, ultimately, a more consistent, integrated vision of domains and objectives (CESP, 2004: 13).

Example

Prematurity and low birth weight indicators are used in the areas of development, adaptation, and social integration due to their relationships with child development and underlying problems. At the same time, in the area of workplace health, are of interest those indicators that permit the monitoring of the Maternity without Danger program (which is focused on the prevention of adverse pregnancy outcomes for female workers). Indicators associated with the use of the preventive withdrawal program are therefore used, but no indicator of pregnancy outcomes has been defined (prematurity or low birth weight, for example) (CESP, 2004).

Furthermore, to generate information that is as accurate as possible, objects and indicators must be defined so as to represent the realities that they need to cover; this requires that the association between an object (the definition given to it) and the indicator(s) corresponding to it, be likewise validated. For example, within the scope of the project to amend the PCS, the Committee explored the links between income (surveillance object) and the "rates of social assistance program recipients" (associated indicator). To that end, the Committee asked the following questions: "What meaning, in fact, was given to this object? Did it actually have to do with income, or did we wish, for example, to measure the degree of social insertion of individuals?" (CESP, 2009: 8). In a case like this one, it is therefore important to clearly establish the manner in which the indicator should inform the object under which it is found.

Moreover, it is important to consider the meaning given to the evolution of an indicator over time, some of these having a less univocal interpretation than others. For example, during its review of the draft plan for the capital region (CESP, 2006), the Committee discussed the rates of voluntary termination of pregnancy (VTP). Firstly, it pointed out that changes in the VTP rate do not have a univocal meaning, such as, for example, the mortality rate associated with cardiovascular disease. The beliefs and values associated with childbearing, the age of procreation, and the decision to terminate or not a pregnancy have changed over time. Furthermore, the classification itself of the VTP rate as a "health problem" can be debated. In fact, the interpretation that one can give to the changes in the VTP rate is itself undergoing evolution.

Lastly, the choice and development of indicators should also be accompanied by ethical considerations relative to the utility of their application.

Example

During its review of the PMSM, the Committee discussed the definition and scope of an indicator relating to the proportion of children and adolescents who wear an orthodontic appliance. According to those in charge, the indicator had the objective of "observing whether social inequalities exist in regard to the financial accessibility of this specialized service" (MSSS, 2008, Theme 1: 96). According to the Committee, this indicator, given the reality that we wanted to measure, raises questions concerning its utility and its validity.

On the one hand, what meaning should be given to the results of this indicator? Does it show anything valid (does it accurately measure the reality that it is trying to describe)? Is it possible, for example, to isolate the reasons that lead to the use of an orthodontic appliance (functional problem, as opposed to an aesthetic problem, for example)? How can one analyze an indicator that would encompass functional, physiological, and psychological problems, or that bears witness to the new aesthetic requirements of the market? (CESP, 2010). On the other hand, since inequalities can already be observed with regard to dental health, including for services that are free, what does the addition of this measurement contribute to what we already know?

On this subject, the Committee recommended that the reflection on this indicator be continued; it was recommended that it be removed if it was deemed to be invalid or of little use.

In conclusion, the scientific process that leads to the shaping of an indicator ultimately requires choices to be made with regard to the inputs which compose the indicator. Work conducted by the World Health Organization (WHO) (Murray, Salomon, Mathers & Lopez, 2002) with regard to summary measures of health reported on the fact that, alongside the numerous studies on these measures, there has been an increase in debates regarding their application in public health. These debates range from technical and methodological issues with regard to the formulation of these different measures, to ethical aspects related to the social values underpinning them—notably concerns regarding distributive justice—and to the use of these measures as levers in allocation decisions. These questions could, with certain variations, be raised in the developments that accompany the implementation of plans (CESP, 2010: 10-11). As the WHO suggests, this would make it possible, on the one hand, to highlight the values that guide the choice of the elements that serve to calculate summary measures, thus encouraging awareness regarding their ethical dimension, and, on the other, to gain a better understanding of the scope and limits of these measures or indicators, particularly with regard to the consequences that they may have for the population.

3.5 PROFUSION OF DATA AND DECISION-MAKING

Decision-making requires quality information to support decisions pertaining to the development of public policies and all other types of intervention. This information can be obtained through the surveillance of the health status and its determinants, but also through evaluation, research, and so on. In the particular case of surveillance, we saw above that the information produced covers a significant number of objects concerning the population's

health status and its determinants; the resulting quantity of information can therefore be considerable.

The profusion of data raises the question of limits to the contribution of information in the decision-making process. Presently, the density and complexity of information often renders its integration difficult. Users of this information, notably planners and decision-makers in health and social services establishments, demand that it be pertinent because, otherwise, its abundance could cause a certain paralysis of thought and action.

Paradoxically, despite this informational abundance and the difficulty of assimilating it, we find that the logic of profusion endures. The influence exercised by the growth of information technologies contributes to creating pressure to collect and access information that is ever more specific and plentiful. The question arises as to whether technical capacity risks defining the need for information. How does this pressure influence the allocation of ever-limited resources?

This line of thought echoes the finding that there is an absence of apparent logic in the construction of health information; it also echoes a strategic issue that undoubtedly merits consideration within the context of the profusion of health data: "too much information kills information" (Perret, 2002: 26). As a matter of fact, as we mentioned with regard to inductive and deductive methods for selecting elements of surveillance plans, it appears that, in many cases, it is a given that the simple availability of information justifies its presence in the plans. The problem is that the availability of data is certainly a necessary criterion of its presence in surveillance plans, but is not sufficient in itself.

This situation has the potential to affect the effectiveness of information in supporting actions intended to improve health. Consequently, in terms of the effectiveness and efficiency of information, the CESP recommends that managers consider the possible negative effects of this problem.

3.6 DATA BANK MANAGEMENT AND PROTECTION OF PERSONAL INFORMATION

Since it constitutes the raw material of surveillance activities, information must be handled with care, particularly when it is personal in nature. Respect for the privacy of individuals and for the confidentiality of information concerning them are fundamental principles of democratic societies, and have been thus been subjected to guidelines on both the legal and administrative levels. From an ethical standpoint, these principles stem from the values of: respect for individuals and their dignity, of individual freedom, and of autonomy.

Within the scope of their activities, surveillance teams use a multitude of files and data banks originating from different sources, mostly from public entities, such as the Vital Events Register (RED) and the ministerial data banks (Med-ECHO). The information coming from these files can be used on its own or added to larger banks of paired data. The information can also originate from surveys conducted for surveillance purposes. All these files and data banks contain a range of information pertaining to various aspects of the life of individuals; information that is sometimes sensitive, when combined with or paired with certain other

information, resulting in a need to regulate the use of the data contained in these banks and to require its rigorous management.

Far from constituting a neutral collection of elements to which one ultimately gives meaning, data can, in itself, convey sensitive information. Is meant by sensitive, data that can violate confidentiality by revealing the identity of an individual or stigmatize a population sub-group, for example, by identifying health problems heavily prevalent in people residing in a particular geographical location (e.g., a neighbourhood) or who share certain distinctive traits (e.g., ethnic groups).

When submitting their projects to the CESP, parties involved in surveillance indicate of their own accord that protection of personal information, privacy, and confidentiality are ethical concerns, among other reasons because it is regulated at the legislative, legal, and deontological levels. In general, the authors of surveillance plans seek to respect the requirements for the protection of personal data. Nevertheless, since the information necessary to carry out surveillance plans is most often requested in a form that does not allow for identification of the persons associated with this information (Art. 38 of the Québec LSP), there is a tendency to deduce that no particular ethical concerns exist for non-personal information. The Committee has a broader understanding of this concern. As such, it recommends that surveillance professionals broaden their reflection from solely taking into account personal or identifying information to also considering the possible effects of the information generated from non-identifying information gathered from the entire population or specific sub-groups. They could, to this end, draw inspiration from the work of the bioethics centre of the Institut de recherches cliniques de Montréal (Demers et al., 2004). We will return to the question of stigmatization a little further on.

Example

In the context of the creation of a paired data bank pertaining to chronic diseases (PMSM, section 1), the CESP asked its managers to report on the rules in effect within their organization—the Institut national de santé publique du Québec, in this case, which was going to host the paired data bank—and to specify the manner in which they would apply to the new data bank.

With the goal of ensuring that the utilization and communication of data required for surveillance of the population's health status be performed while respecting confidentiality and privacy, and that the values of freedom, dignity, and autonomy of individuals and groups be thus preserved, the Committee recommended to project managers that the policies (rules) relative to the protection and management of data banks in effect within the organization hosting the paired data bank on chronic diseases, as well as the manner in which these policies would be applied to this data bank, be provided in a document that would be accessible and identified to this end (CESP, 2010).

The Committee is also concerned with making accessible the type of measures taken by organizations, such as the Infocentre de santé publique, to protect the information used for the purposes of the PCS. While the Infocentre's legal and administrative response was adequate with regard to these concerns, the Committee however insisted that these rules be

put in writing and made accessible on its portal. Also, the document must be written in clear, accessible language so as to enable any user to clearly understand the relevant confidentiality and privacy issues and the measures taken to contain the underlying risks. It is the responsibility of the State to protect the information contained at the Infocentre, notably through the rigorous application of adequate security measures.

3.7 ETHICAL CONCERNS WITH SURVEYS

The present summary does not cover the Committee's opinions on sociosanitary surveys undertaken for surveillance purposes. Since surveillance plans can select these surveys as a source of information, we will discuss, here, the general concerns that the Committee has addressed in its opinions on surveillance plans.

The large-scale surveys developed and conducted by Statistics Canada, such as the Canadian Community Health Survey (CCHS), borrow from different review mechanisms relative to content and methodology, while at the same time addressing ethics-related questions. To our knowledge, however, no mechanisms exist that are dedicated to a review, properly speaking, of the ethical dimension of these large projects. The CCHS constitutes, however, an important source of information for the PCS, as well as for the PMSM. To this end, the Committee is of the opinion that it is necessary to promote the ethical review of all surveys with which Québec is involved. The ethical review of such projects should take into account, in particular, the diversity of the population sub-groups concerned, by encouraging, for example, the participation of territories and provinces.

As with surveillance plans and for the same reasons, it is important to clearly determine the purposes of a survey, when such a survey is performed for surveillance purposes. Assigning other purposes to it (research, evaluation, or other) would lead to misleading the plan's recipients about the eventual uses of the collected information.

The administration of questionnaires undoubtedly has different implications depending on whether the information is collected for surveillance or research purposes, or for the purpose of detecting individuals at risk of a health problem. Interviewer supervision will probably not be the same if the questions asked risk touching on specific vulnerabilities or involve special follow-up. In addition to producing possible adverse effects for people, the use of a diagnostic-type tool, for example, would involve a number of conditions to its implementation, including the availability of services when a person is defined as at-risk for, or is diagnosed with, a mental or psychosocial health problem.

3.8 RISK OF STIGMATIZATION IN THE CROSS-REFERENCING AND DISSEMINATION OF DATA

As mentioned above, increasingly refined technologies enable us to handle a larger and more complex quantity of data, notably in regard to cross-referencing, and to generate more precise information. Possessing such a processing capacity while having access to a considerable quantity of data confers significant responsibility on the people manipulating it, considering the possible consequences for the population.

For example, the cross-referencing of data, which is at the heart of surveillance operations, could cause harm to certain groups of the population. Such operations could lead to the indirect identification of people or groups of people and contribute to their stigmatization.⁵ Indeed, this cross-referencing enables the identification and the fairly accurate description of groups at risk of stigmatization: for example, groups disadvantaged at the socio-economic level and exhibiting behaviours considered at-risk, to which particular health problems would be associated.

For the authors of surveillance plans (in the present case, those of the PCS and of the PMSM), it appears difficult to anticipate all the possible cross-references of certain variables within a single data bank and to foresee the results of this cross-referencing. In this regard, the Committee has recommended that surveillance professionals be vigilant during these operations, with a view to avoiding situations in which this cross-referencing could expose a group or groups of the population to the risk of undue stigmatization. The CESP invites plan authors to consult it if the development of a particular analysis plan raises ethical concerns regarding which the Committee's opinion would be useful; the same applies to dissemination activities.

Example

As mentioned above, an increasing amount of data is made available on small geographical scales, primarily by postal code and by neighbourhood. These "correspond to sociological territories defined by local communities in partnership with the DSP. They are used in order to meet the representation needs of organizations acting at the local level. The scale of a neighbourhood is situated between a CLSC territory [local community service centre] and a census tract. Lastly, we note that neighbourhoods are contained within CLSC territories".⁶

Cases may exist in which the number of people defined by a neighbourhood is so small that it would be possible to establish their identity. Furthermore, small sub-groups sharing certain socio-demographic attributes and standing out because of their neighbourhood could be stigmatized due to an association with characteristics deemed undesirable by the population in general (e.g., particular health problems).

Within the context of the review of the *Plan régional de surveillance de Montréal* [Montreal regional surveillance plan], the project directors, faced with these concerns, proposed not to use neighbourhood data when this data referred to too-small a number of people. Moreover, in other cases in which stigmatization could be present, they proposed to point out the contexts and social determinants found at the source of the problems indicated, thereby aiming to minimize the risk. Lastly, in the project specifications, they also raised the possibility of working in partnership with the local and community parties concerned (CESP, 2012).

⁵ For further information on this subject, we invite you to consult Déry & Filiatrault, (2013).

⁶ Source: <http://emis.santemontreal.qc.ca/outils/atlas-sante-montreal/caracteristiques-de-la-population/definition-des-decoupages-geographiques/>, visited on December 9, 2011.

The importance of the risk of stigmatization led the CESP to reaffirm the responsibilities of surveillance professionals and authorities with regard to their work. They must be able to clearly justify the choices presenting stigmatization risks to members of the groups concerned. The solutions proposed by the plan directors notwithstanding, the stigmatization risk resulting from certain portraits could constitute one of the reasons that could be invoked to limit dissemination to certain key parties, for example.

Generally speaking, the Committee recommends that surveillance professionals be explicit when disseminating results, as well as the surveillance plan itself, regarding the ethical dimensions raised and the manner in which these dimensions have been integrated into their work. In the hope of preserving the relationship of trust with the population, it is necessary to demonstrate that the potentially negative effects of a project have been taken into consideration before its deployment. In fact, surveillance without any risk of stigmatization is not realistic; this risk exists wherever health problems have been identified in sub-groups of the population. Consequently, the Committee recommends that all professionals working in surveillance indicate, as clearly as possible, the stigmatization risks and their scope, so as to establish the methods of reducing, if not the risk itself, at least its effects on individuals or groups of the population.

3.9 ISSUES ASSOCIATED WITH THE SELECTION OF DISSEMINATED INFORMATION AND THE TERMINOLOGY USED

The dissemination of information resulting from surveillance is not a step like the others. Although each of the steps are important, dissemination is the activity through which the main purpose of the surveillance is achieved, i.e., that of informing, of delivering information useful to decision-making. As such, dissemination constitutes the reason itself for the surveillance, the outcome of the process. This crucial step must be planned at the very start of a plan's development.

The dissemination of surveillance results aims to offer, to some degree, a window into the health status of the population, of some of its sub-groups, and of the factors influencing this health status. Through the information that they disseminate, public health authorities broadcast the health problems observed, the population groups that they are concerned about, the programs that they intend to set up to resolve these problems, the health determinants on which they intend to act or lead other sectors to act, and so on. But this information is also addressed to the population, with the aim of informing it so as to improve its ability to make reasoned decisions relating to health; adopting preventive behaviours, for example.

The pursuit of these objectives requires a responsible, fair, and respectful approach to the groups to whom the information is addressed, all the more as one of these groups, the population, constitutes its primary subject. In some cases, this could translate into a desire to agree on the methods for the dissemination of information with certain sub-groups targeted by the surveillance, with a view to mitigating any negative effects; the risk of stigmatization, for example.

Faced with certain health problems, the temptation can be great to emphasize a single determinant, with the effect of reducing the importance of others—that are possibly just as influential and on which action could be taken—in the causal dynamic. For example, the CESP's discussions, during its review of the theme of environmental health in the context of the PMSM, provided a good illustration of the sensitivity that exists with regard to environment-related risks. The perception of environmental risks to health, notably those associated with air and water, is particularly acute in the population. Consequently, the Committee formulated a warning with regard to the possible effects of disseminating information resulting from surveillance of these factors; the perception of risk could then be exacerbated, and therefore biased, if such dissemination isolated environmental factors from other factors, such as socio-economic determinants, for example.

Another ethical concern was raised in the context of examining the section of the PMSM concerning oral health. As the next box illustrates, this concern pertained to indicators serving to measure social impact and to the vigilance that their utilization requires.

Example

In the oral health section (PMSM), two quality of life indicators put forward the notion of social disadvantage linked to oral health. These indicators would make it possible, in practice, to measure the social impact of oral health problems, both for individuals and for society, by evaluating the "number of people who were unable to attend to their day-to-day activities due to problems in the mouth, with teeth, or with their prosthetics" (PMSM, Theme 1, pg. 98). In addition to questioning the validity of these indicators, which was an issue here, it was the scope of their message.

While recognizing the possibility that a person affected by oral health problems could be affected in terms of his/her self-image and experience problems associated with self-esteem, how can this data be analyzed within the context of the development of social standards that are increasingly higher with regard to appearance (consider the market for teeth whitening, for example, and this despite the potential risk to dental health)? Do these indicators not exceed the scope of individual factors? And, more concretely, could they lead to reinforcing standards of "aesthetics"?

The Committee recommended that the authors of the oral health section clearly specify what the selected indicators could mean, and evaluate their validity and pertinence, given the potential effects that could result, notably in relation to the reinforcement of social standards whose underlying value is not necessarily health and well-being (CESP, 2010).

As previously mentioned, a surveillance plan must state the main objectives of the proposed surveillance, the topics selected, and their justification; in short, what one intends to do with the data that will be made available. Communicating the existence of a surveillance plan constitutes, in itself, an initial outreach effort, which is accompanied by the same requirements for accessibility of the document by those we seek to reach. Transparency and respect for others are the primary values in this case.

Furthermore, harmonization of the vocabulary used by surveillance professionals working in different subject areas, through the establishment of a glossary, for example, could also contribute to better comprehension and to the sharing of common issues (CESP, 2010). In fact, a glossary could avoid polysemy in the definition of terms used by surveillance stakeholders and could assist non-experts in better understanding these terms. The accessibility of a plan must be understood to include both the ability to understand a document and its physical or virtual access. This requirement necessitates, among other things, that the text be intelligible and correct, i.e., that the terms used be first and foremost easy to understand (with the help of a glossary if needed) and that they be appropriate in the circumstances. In short, to ensure transparency in the performance of the surveillance function and to increase its pertinence and effectiveness—i.e., its ability, at the end of the day, to contribute to improving the population's health—the surveillance plan must be designed from a pedagogical perspective. As the following box illustrates, certain terms have a relative clarity, and their use could suggest a more general concept without specifying their full meaning.

Example

Consider the use of the term "non-identifying" [*dénominalisé*] in the specifications of the amendment project of the PCS. Referring to the type of data used in the MADO-CHIMIQUE system, one can read that: "As is planned for the *Common Surveillance Plan* project at the Infocentre de santé publique, a 'non-identifying' excerpt (i.e., without the surname, given name, and postal code of the affected person) from the individual information file will only be accessible by the Infocentre de santé publique team and two other resources within the INSPQ [...]" (2009: 12).

For the Committee, the emphasis placed on the term "non-identifying" could create a sort of "blindness" with regard to the risk of disclosure: while it was clearly specified what was meant by "non-identifying excerpt",⁷ other, identifying information were going to be used and could have led to people being identified (CESP, 2009).

In conclusion, the CESP can conceive that these requirements might be satisfied by distinct, summary, and general texts that would include hyperlinks, allowing interested people to learn more about the complete plan. Also, the production of a glossary of the more technical terms may likewise prove useful.

⁷ Which does not include either the surname or given name, or the postal code of the person affected.

4 THREE MAJOR THEMES TO CATEGORIZE ETHICAL CONCERNS

Generally speaking, public health discourse is based on a number of values such as beneficence, non-maleficence, fairness, responsibility, autonomy, respect for persons and groups, and so on. Public health seeks to put these values into practice through the actions that are undertaken by its various essential functions, including surveillance.

While it is relatively simple, at the level of discourse, to mention values that motivate our actions, it is often much less obvious to translate these values into concrete actions. The complexity inherent in the definition of health, the lack of time, as well as the feeling of inability to address ethical dimensions often render ethical reflection arduous and complex for public health stakeholders. Furthermore, the implementation of some values could enter into conflict with others. A classic example is the tension resulting from the targeting of vulnerable groups to facilitate intervention (beneficence, improving health) and the risk of stigmatizing the people that we seek to support (violation of human dignity and autonomy). The process used by the CESP in reviewing projects that are submitted to it aims in particular to explicitly highlight the tensions between values underlying the projects.

Through the present summary report on the CESP's work, we can identify three major themes around which all ethical concerns revolve: *specificity*, *balance*, and *spaces for dialogue*. These themes are interdependent. We will address them very briefly here, but in a manner that is sufficiently illuminating, we believe, to support proper surveillance practices; these themes encourage the consideration of values that have been recognized as the most important in the analysis of draft surveillance plans.

4.1 SPECIFICITY

Specificity first concerns the purpose of the surveillance. This is expressed through the development of the overall guidelines for a project and the strategic vision on which the planning of sociosanitary activities is based. Specifying also means explaining the choice of elements retained in a plan (themes, objects). Defining the guidelines consists in clarifying them for oneself and for others, i.e., the people involved in a project as subjects of the surveillance products or as users of the information produced: the population and its sub-groups, health care workers, the various partners and decision-makers.

The primary mission of surveillance being to produce information useful for decision-making, it is important to be able to make intelligible the information produced. Surveillance stakeholders must manipulate a large quantity of data so as to deliver information that is both clear and comprehensible to its users; information that meets their needs and enables them to take action.

Specificity also concerns the values underlying the exercise of surveillance. Making explicit the values that guide and justify it, such as respect for persons, autonomy, beneficence, as well as transparency, surveillance stakeholders positively contribute to the relationship of trust with the population and partners.

Lastly, it is important to keep in mind the information environment in which surveillance is exercised today. The advancement of information and communication technologies has multiplied the sources of information. Public entities cannot escape this trend. Large producers of information themselves, about health in this case, they find themselves within a dynamic at the heart of which there is an issue of “attention economy” (Kessous, Mellet, and Zouinar, 2010). The idea here, for surveillance stakeholders, is therefore to be parsimonious, i.e., to resist the temptation to always produce more information in order to be heard by decision-makers. The utility of information produced is not improved by its multiplication.

4.2 BALANCE

This is a key word. Balance takes on a very broad meaning here, referring to the idea of due weighing of the elements of a whole, of overall consistency, and of sufficiency. Balance also refers to the notions of fairness and reasonableness. From an ethical perspective, one seeks balance between the purposes and the means proposed in a surveillance plan, on the one hand, and between the values and standards associated with this plan, on the other. Are the values here in conflict with one another or with certain normative aspects that also guide the plan (a public health plan or program, for example)?

A back-and-forth movement between values that are judged to be important in the situation and the salient elements of a surveillance plan, for example, allows for a critical review of the latter, the aim being to eliminate inconsistencies and contradictions between ideal and real situations. To paraphrase Malherbe (2007: 19), this process aims to reduce the gap, with regard to values, between discourse and practice.

The Committee has often evoked this concept of balance in its opinions, for example:

- With regard to a fair and pertinent representation of each of the themes within a surveillance plan (e.g., mental health or health in the workplace appear to be underinvested compared to other themes).
- Between positive and negative objects and indicators, which could encourage the development of promotion and intervention strategies based on positive levers such as solidarity and social cohesion as well as empowerment, while respecting the autonomy of individuals and communities.
- With regard to the treatment of various sub-groups of the population, to ensure fairness. The consideration, in surveillance, of more disadvantaged sub-groups of the population constitutes the starting point for the efforts to reduce social inequalities in health. It is necessary to target less affluent sub-groups, yes, but only while taking out the risk of stigmatizing them.
- With regard to efforts given to the creation and implementation of a surveillance plan that must be commensurate with the utility and effectiveness of the information produced as it relates to its contribution to improving the population's health, no more, no less.
- Lastly, with regard to the transversal or complementary nature of the objects and indicators, so as to ensure that themes can enrich one another, in order to offer a more integrated view of health.

To summarize, seeking balance involves moving back and forth between the overall vision of the plan and its individual elements, and reflection on the values that are put into practice.

4.3 SPACES FOR DIALOGUE

The themes of specificity and balance could not be fully realized without the contribution of input that is external to the surveillance. This external input, given by members of the population, stakeholders, partners, and even decision-makers, can contribute to the quality assurance of actions taken in this area.

The creation of spaces for dialogue invites a relationship of reciprocity: on the one hand, public health expertise in surveillance becomes more accessible to the population and to partners; on the other, the layman's knowledge,⁸ the realities on the ground and the contribution of other types of expertise feed and enrich public health expertise. External contribution can, among other things, allow us to:

- obtain a better understanding of health problems and associated determinants (allow us to determine, for example, the limits with regard to the surveillance of an object, i.e., what surveillance covers and does not cover for a given health problem);
- clarify purposes and guidelines;
- question certain choices (objects of surveillance, for example) or better justify them;
- establish a dissemination plan that takes into consideration, in particular, the needs expressed by the primary users (to produce information useful to decision-making);
- verify the acceptability (and often therefore the risks for population sub-groups) of certain messages conveyed by the surveillance products.

Depending on the type of contribution sought, spaces for dialogue can take different forms: consultation of certain key stakeholders (e.g., decision-makers, health network workers, representatives of community organizations, members of associations that provide assistance to various causes, members sitting on an elected regional body), consultation of representatives of population sub-groups affected by a particular health problem, or use of mechanisms such as regional population forums. The use of spaces for dialogue is embodied therefore in a greater participation of parties who are key to the development and implementation of surveillance plans through these different mechanisms. And making use of these spaces for dialogue means strengthening values associated with the autonomy of people and groups, trust, openness, and responsibility.

⁸ Layman's knowledge is used here in contrast to expert, scientific, or academic knowledge.

5 QUESTIONS FOR FURTHER REFLECTION

In some of its opinions on surveillance plans, the Committee raised issues that invite to further targeted reflection. They are listed here:

- indicators, notably composite indicators, which seem to raise a larger number of ethical concerns. For example, the development of an indicator on the burden of disease;
- the systematic use of variables, for a vast group of surveillance objects, without the justification being clearly explained; ethnicity, for example;
- the benefits and risks associated with the dissemination of information resulting from surveillance, and more particularly, consideration of the risk of stigmatization resulting from this dissemination or strengthened by it;
- support for the creation of spaces for dialogue between surveillance stakeholders, users, and the subjects of surveillance;
- the ethical aspects specific to innovative practices, i.e., those associated with the objectives pursued by the elaboration of prospective scenarios, or by the identification of priority or emerging problems;
- the technological imperative and the profusion of objects and indicators.

The Committee will engage in dialogue with the main parties involved in surveillance, with a view to determining the manner in which they can collaborate to clarify these topics. Various forms of exchanges (seminars, training sessions, discussion groups, presentations, written papers, symposiums, etc.) could be planned with a view to sharing information and enriching respective practices.

The development of mechanisms for the evaluation of surveillance activities by those in charge could also benefit from the Committee's expertise with a view to integrating the ethical dimension. Based on the experience of the CESP in reviewing surveillance plans and on the literature, the Committee's staff has developed a tool for analyzing surveillance plans (Déry, Filiatrault & Laporte, 2012). Initially designed to support the Committee's work, this tool could support surveillance stakeholders by providing a framework for the development of future surveillance plans, their implementation, or their evaluation.

6 CONCLUSION

The ethical concerns outlined in the present summary essentially translate "field" knowledge, that is, they are drawn from the deliberative experience of the CESP through its review of surveillance plans that were submitted to it between 2003 and 2012. The critical examination of the Committee's experience during the first ten years of its practice has highlighted the knowledge that it has developed, but has also enabled the identification of questions that remain, which represent as many opportunities to continue reflection with parties involved in public health surveillance.

The knowledge acquired through the CESP's experience is primarily reflected in the tool that its staff developed to support the analysis of surveillance plans (Déry, Filiatrault & Laporte, 2012). The Committee invites parties involved in surveillance to make use of this tool to support the development of a comprehensive vision of their surveillance plans. It could also assist in ensuring consistency and balance between the different elements of which they are composed. The choice of objects and indicators, for example, should enable the construction of a fair representation of a population's health, that is to say, of the different health problems and determinants associated with them. The Committee also stresses the meaning given to a plan, its purpose, its objectives, and, of course, its limits. These different elements will benefit from being explicit and comprehensible with a view to being shared with the different users of the information resulting from a surveillance plan. Lastly, the Committee considers the initiation of dialogue with these different categories of users as a *sine qua non* condition of the exercise of any surveillance so it can be useful to those it serves: not only is the consideration of users' needs (recipients of the information) necessary, particularly at the start of the process, but these users can also make a real contribution to the periodic evaluation of surveillance systems. Despite the real difficulties that this poses, the initiation of dialogue with the population, at least with the population sub-groups most concerned by the impacts of the surveillance, constitutes a challenge to be taken up by those in charge of surveillance.

We have observed natural convergences between the observations of the CESP and elements reported in the literature on ethics in surveillance, notably with regard to confidentiality and privacy. These elements are moreover being regulated by the legal frameworks of the Canadian provinces and most countries. The tool for identifying ethical concerns is also echoed in this literature, for example, with regard to the transparent and explicit nature of purposes, the concept of proportionality (balance between benefit and harm, fair representation of population groups), and the importance of consulting the target groups and the users of the information that will be produced.

In conclusion, the Comité d'éthique de santé publique [Public Health Ethics Committee] invites parties involved in surveillance to remain critical with regard to their practice, to regularly question and test automatisms by keeping in mind the three themes that encompass the ethical concerns raised here to date: specificity, balance, and spaces for dialogue.

REFERENCES

CESP opinions on surveillance plans

- 2012 *Avis sur le Plan régional de surveillance de la région de Montréal 2011-2015*, Institut national de santé publique du Québec, gouvernement du Québec.
- 2011a *Avis sur le projet de Plan ministériel multithématique – Volet hémovigilance*, Institut national de santé publique du Québec, gouvernement du Québec.
- 2011b *Avis sur le développement d'un système de surveillance des expositions à l'amiante et des maladies qui y sont reliées*, Institut national de santé publique du Québec, gouvernement du Québec.
- 2011c *Avis portant sur le projet d'amendement pour intégrer les sources de données et les renseignements ajoutés au Fichier des tumeurs du Québec*, Institut national de santé publique du Québec, gouvernement du Québec.
- 2010 *Avis sur le projet de Plan ministériel de surveillance multithématique*, ministère de la Santé et des Services sociaux, gouvernement du Québec.
- 2009 *Avis sur un amendement au Plan commun de surveillance*, ministère de la Santé et des Services sociaux, gouvernement du Québec.
- 2006a *Avis sur le projet de Plan régional de surveillance de la région de la Capitale-Nationale? (région 03)*, ministère de la Santé et des Services sociaux, gouvernement du Québec.
- 2006b *Avis sur le projet de Plan régional de surveillance en santé publique – région de Chaudière-Appalaches*, ministère de la Santé et des Services sociaux, gouvernement du Québec.
- 2005a *Avis sur le projet de Plan régional de surveillance de la région des Laurentides*, ministère de la Santé et des Services sociaux, gouvernement du Québec.
- 2004 *Avis sur le projet de Plan commun de surveillance de l'état de santé de la population et de ses déterminants 2004-2007*, ministère de la Santé et des Services sociaux, gouvernement du Québec.

Literature

Beauchamp, T., Cook, R., Fayweather, W., Raabe, G., Thar, W et collab., 1991. « Ethical Guidelines for Epidemiologists », dans *Journal of Clinical Epidemiology*, 44 S1 : 151S-169S.

Bouthillier, L. et F. Filiatrault, 2003. *Exploration du phénomène de stigmatisation au regard des activités de surveillance de l'état de santé de la population*, Montréal, Ministère de la Santé et des Services sociaux.

Comité d'éthique de santé publique, 2005b. *Sondage omnibus de la Direction de santé publique de Montréal - printemps 2005*, Montréal, ministère de la Santé et des Services sociaux.

Commissaire à la santé et au bien-être, 2008. *Explorer les enjeux dans le domaine de la santé et du bien-être*.

Childress, J.F., R.R. Faden et collab., 2007. « Public Health Ethics: Mapping the Terrain », dans *Journal of Law and Medical Ethics*, 30 : 170-8.

Demers DL., Fournier F, Lemire M, Péladeau P, Prémont M-C et Roy DJ, 2012. *Le réseautage de l'information de santé : Manuel pour la gestion des questions éthiques et sociales*, Montréal, Centre de bioéthique, IRCM, 2004, 268 p.

Désy, M. et F. Filiatrault, 2013. *La dimension éthique de la stigmatisation en santé publique (outil de réflexion)*, INSPQ, Québec.

Désy, M., Filiatrault, F. et Laporte, I., 2012. « Outil d'analyse éthique des plans de surveillance », dans Institut de la santé publique et des populations des Instituts de recherche en santé du Canada. *Éthique en santé publique et des populations : cas tirés de la recherche, des politiques et de la pratique*, Centre conjoint de bioéthique de l'Université de Toronto, Ottawa.

Etches, V., J. Frank, E. Di Ruggiero et D. Manuel, 2006. « Measuring Population Health: A Review of Indicators », dans *Annual Review of Public Health*, 27 : 29-55.

Fairchild, A.L., 2003. « Dealing with Humpty Dumpty: Research, Practice, and the Ethics of Public Health Surveillance », dans *Journal of Law, Medicine and Ethics*, 31 : 615-623.

Fairchild, A.L. et R. Bayer, 2004. « Public Health Ethics and the Conduct of Public Health Surveillance », dans *Science*, 303 (5658) : 631-2.

Friedman, D. J., E.L. Hunter et R.G. Parrish, 2002. *Shaping a Health Statistics Vision for the 21st Century*. Final Report, November 2002, [s. l.], Centers for Disease Control and Prevention, National Center Health Statistics et National Committee on Vital and Health Statistics.

Heilig, C.M., P. Sweeney, 2010. « Ethics in Public health Surveillance » dans L. Lee, S.M. Teutch et S.B. Thacker, *Principles and Practice of Public Health Surveillance*, Chap. 9, Oxford U.P., Oxford.

Hausman, D., 2012. « Measuring or Valuing Population Health: Some Conceptual Problems » dans *Public Health Ethics*, 5, 3, pp. 229-239.

- Joint Center for Bioethics, 2005. *Stand on Guard for Thee, Ethical Considerations in Preparedness Planning for Pandemic Influenza*, rapport, Toronto : Université de Toronto, URL : http://www.jointcentreforbioethics.ca/publications/documents/stand_on_guard.pdf.
- Kass, N.E., 2001. "An Ethics Framework for Public health", dans *American Journal of Public Health*, 91 (11) : 1776-82.
- Kessous, E., K. Mellet et M. Zouinar, 2010. « L'économie de l'attention : Entre protection des ressources cognitives et extraction de la valeur », dans *Sociologie du travail*, 52 (3) : 359-73.
- Lee, L.M., C.M. Heilig et A. White, 2012. « Ethical Justification for Conducting Public Health Surveillance Without Patient Consent », dans *Health Policy and Ethics*, 202 (1) : 38-44.
- Legault, G.A., 1999. *Professionnalisme et délibération éthique*, Sainte-Foy : Presses de l'Université du Québec.
- Malherbe, J.F., 2007. *Sujet de vie ou objet de soins? Introduction à la pratique de l'éthique Clinique*, Fides.
- J. L. Murray, F. A. Salomon, C D. Mathers & A. D. Lopez (dir.), 2002. "Concepts, Ethics, Measurement and Applications" dans *Summary Measures of Population Health (SMPH)*, OMS.
- Ministère de la Santé et des Services sociaux (MSSS), 2008. Plan ministériel de surveillance multithématique, en collaboration avec l'Institut national de santé publique du Québec, gouvernement du Québec.
- Ministère de la Santé et des Services sociaux (MSSS), 2007. *Cadre d'orientation pour le développement et l'évolution de la fonction de surveillance au Québec*, Direction générale de santé publique, gouvernement du Québec.
- Nuffield Council on Bioethics, 2007. *Public Health: Ethical Issues*, Cambridge, Cambridge Publishers Ltd.
- Parizeau M.H., 1996. « Éthique appliquée » dans M. Canto-Sperber (dir.) *Dictionnaire d'éthique et de philosophie morale*, tome 1, Paris : Presses universitaires de France (PUF).
- Perret, B., 2002. *Indicateurs sociaux, État des lieux et perspectives*, Les Papiers du CERC n° 2002-01, janvier 2002 (Conseil de l'Emploi, des Revenus et de la Cohésion sociale).
- Petrini, C., 2013. « Ethics in Public Health Surveillance », dans *Annali dell'Istituto Superiore di Sanita*, 49 (4) : 347-353.
- Plant, A.J. et R.L. Rushworth, 1998. « Death by Proxy: Ethics and Classification in Epidemiology » dans *Social Science and Medicine*, 47 (9) : 1147-53.
- Romaguera, R., German, R. & Klaucke, D., 2000. « Evaluating Public Health Surveillance », dans Lee, L., Thacker, S., St-Louis, M. & Teutsch, S. *Principles and Practice of Public Health Surveillance*. Oxford U.P., Oxford.

Roy, M. et M. O'Neill, 2012. *La Salutogénèse. Petit guide pour la promotion de la santé*, PUL.

Rubel, A., 2012. « Justifying Public health Surveillance: Basic Interests, Unreasonable Exercise, and Privacy », dans *Kennedy Institute of Ethics journal*, 22 (1) : 1-33.

Snider, D.E. et D.F. Stroup, 2000. « Ethical Issues », chap. 9, dans S.T. Teutsch et R.E. Churchill (dir.), *Principles and Practice of Public Health Surveillance*, Oxford U.P., Oxford.

Thacker, S.B., J.R. Qualters et L.M. Lee, 2012. « Public Health Surveillance in the United States: Evolution and Challenges » dans *CDC's Vision for Public Health Surveillance in the 21st Century*, U.S. Department of Health and Human Services, Supplement MMWR, vol. 61, July 27, Centers for Disease Control and Prevention.

Weinstock, D., 2007. « Qu'est-ce qui constitue une donnée probante? Une perspective philosophique », Compte-rendu de conférence (version préliminaire, pour discussion), Atelier d'été Centres de collaboration nationale en santé publique « Tout éclaircir », Baddeck, Nouvelle-Écosse, 20-23 août 2007.

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