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PUBLIC PARTICIPATION IN NATIONAL PREPAREDNESS AND RESPONSE PLANS FOR PANDEMIC INFLUENZA: TOWARDS AN ETHICAL CONTRIBUTION TO PUBLIC HEALTH POLICIES

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Abstract: Faced with the threat of pandemic influenza, several countries have made the decision to put a number of measures in place which have been incorporated into national plans. In view of the magnitude of the powers and responsibilities that States assume in the event of a pandemic, a review of the various national preparedness and response plans for pandemic influenza brought to light a series of extremely important ethical concerns. Nevertheless, in spite of the recent emergence of literature focusing specifically on the ethical aspects of pandemics, too few studies explicitly examine public participation as one means of ethical contribution to public health policies. Thus this article seeks, in the first place, to present an analysis of the various national preparedness and response plans for pandemic influenza, and secondly, to outline the role that the plans envisage for ethics and more importantly for public participation.

Keywords: *pandemic, influenza, public health, public participation, ethics.*

In response to the challenge that the different forms of the flu virus present to public health authorities around the world, many member states of the WHO have developed a number of measures aimed at preventing and combating a possible pandemic. These measures are outlined in national plans that have been produced by the agencies or ministries in charge of public protection should a pandemic occur. These plans were put into action during the recent H1N1 influenza pandemic in 2009. Acting at different levels (planning, coordination, surveillance, prevention, containment, health care and communication), the response actions encompass a variety of state-of-the-art methods to increase effectiveness in protecting and preserving public health. Given the magnitude of the powers and responsibilities assumed by the State when pandemics occur, an analysis of the various national pandemic influenza preparedness and response plans points to a number of significant ethical concerns. However, in spite of the increase in literature focusing on the ethical issues relating to pandemics (Thompson, 2006, 1-11; Wynia, 2007, 1-4; Kotalik, 2005, 422-431; Gostin & Berkman, 2007, 122-176; Comité d'éthique de santé publique (Gouvernement du Québec), 2006), there is little specific focus on how public participation could be an important factor in the ethical implementation of public health interventions during a pandemic (Uscher-Pines, 2007, 32-39; The Keystone Center. 2007)[1].

Insofar as citizen participation (that is, the involvement of the lay population in the implementation of public health measures) is considered essential to the success of these plans, and in view of the restrictions which the population could endure in the event of a pandemic emergency, public participation is a fundamental ethical issue to which the experts charged with developing and administering the plans must devote themselves. Because beyond the expertise needed by the authorities for public protection, there are also intangibles, such as beliefs, values and local knowledge, that are fundamental conditions through which human actions can be accomplished and justified, whether in public health or elsewhere. From that point of view, lay citizens unavoidably become essential actors on

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whom the authorities must rely to attain their objectives and fully exercise their powers.

In order to shed new light on these topics, this article will, firstly, present its analysis of several different national plans for pandemic influenza preparedness and response; and secondly, it will indicate the weight these plans give to public participation either within the interventions (i.e. role of local communities), or within communication plans and ethical frameworks. This paper will then offer arguments and methods that might help decision makers in their development of management structures for pandemics: structures that would be both more efficient and more transparent, and thus on the whole much more justifiable from an ethical point of view.

THE CHOICE OF PLANS STUDIED AND THE ANALYTIC FRAMEWORK

Over the last few years, given the consequences of a possible influenza pandemic for public health world-wide, a large number of countries across the world have regularly published updated versions of their plans. Several criteria were used in the choice of the plans selected for this study. They had to be available on line, in either French or English. Furthermore, emphasis was placed on the use of a good representative sample, from around the globe, of what authorities are doing to prepare for an influenza pandemic. Finally, the only plans selected were those developed by the highest relevant authority in each of the countries. Thus in countries in which the political system is comprised of several levels of government (in federal states such as the United States or Canada, for example), it was deemed preferable to restrict the research to plans developed by the highest level in the federal government. Thus for Canada, the plan chosen was developed by the Public Health Agency of Canada (Public Health Agency Of Canada, 2006), while for the United States, the plan chosen for analysis came from the White House (The White House. 2005).

The research was conducted from 2006 to 2009. It did not take into account any plans (or any changes to those plans) that have been published since then. In total, twenty-four plans were examined: those of the WHO, Australia, Belgium, Brazil, Burkina Faso, Canada, Chile, China (Hong Kong), Czech Republic, France, Germany, Italy, Japan, Korea, New Zealand, the Netherlands, Norway, the Philippines, Sweden, Switzerland,

Thailand, the United Kingdom, the United States and Vietnam.

The analytic framework for studying the plans had three main themes: the general structure of the plans, ethical questions, and the role of the public. The objective of the first theme was to discover measures and goals that, because of their importance, and putting aside national differences, were included in all of the plans. The second theme focused on ascertaining whether the plans studied included discussions of the ethical principles and values guiding the application of public health measures. The main concern here was to determine the extent to which public participation was seen as an ethical issue. Finally, for the third theme, the objective was to examine more carefully the role given in these plans to the lay citizen in general.

Even though the plans were examined in their entirety, keyword searches of the PDF documents were carried out with a view to conducting the most exhaustive search possible of those parts of the documents dealing with the chosen themes. The analysis of the plans was restricted exclusively to the documents; it only sought to determine whether or not they dealt with the study questions.

APPRAISAL OF THE PLAN CONTENTS USING THE ANALYTIC FRAMEWORK

General Structure of the Plans

In order to understand the general structure of the different national plans, it is important to know that the WHO has issued a checklist containing a number of recommendations directed at the national authorities responsible for preparing for an influenza pandemic (WHO/Global Influenza Programme, 2005). These recommendations focus on the two fundamental aspects of most of the plans. The first is the description of the risk levels for a pandemic (called *phases* in most of the plans). There are six phases of increasing strength, where one is the lowest risk level, and six is the highest level. The second element deals with the levels of intervention anticipated for each of the phases defined by the WHO plan. The intensity of the levels of intervention increases in proportion to the perceived risk. The levels are as follows: 1) planning and coordination (who does what *in situ*?) 2) surveillance and evaluation (what is known about the virus?) 3) prevention and control (how to prevent the transmission

and spread of the illness?) 4) the response of health systems (how should care be organized?) 5) communication (how to organize the dissemination of information between the authorities and the public?).

These two elements shape the general recurring structure in the plans and, although the wording differs from one State to another, they appear in almost all measures. Therefore they provide a good synthesis of what is considered essential in terms of action and planning. Regarding the levels of intervention, particular attention had to be paid to communication strategies, specifically the kinds of communication with the public envisaged by the authorities. The results of the analysis of these strategies are presented further on in the text.

Ethical Questions

In spite of the obvious importance of ethical questions associated with issues such as the distribution of resources (vaccines and a shortage of beds for example), or with measures of surveillance or control that could result in restrictions on individual freedom, the majority of the plans studied did not contain an ethical framework. Some indicated the importance of ethics, but without further elaboration (absence of a developed ethical framework). Three plans are an exception to this rule: those of Canada, New Zealand and Switzerland. The Canadian plan prioritizes the principles guiding the implementation of interventions should there be a pandemic. This framework seeks to balance the ethical principles related to public health with the clinical ethics applicable in the same situations. However, given the urgency and the global nature of this menace for society, in the end the Canadian plan gives precedence to the ethical principles related to public health. The plan thus sets forth six overriding principles: 1) to protect and promote the public's health 2) to ensure equity and distributive justice 3) to respect the inherent dignity of all persons 4) to resort to the least restrictive measures 5) to optimize the risk/benefit ratio, and 6) to work with transparency and accountability.

The Swiss plan also sets forth certain overriding principles that should guide the public health authorities, but focuses more on the allocation of vaccines when resources are being rationed. Thus the ethical framework of the Swiss plan suggests two principles that it considers essential to a successful response to an influenza pandemic. The two principles are the protection of life and solidarity. The hope is that the focus on solidarity

will highlight the importance, for all those affected by the pandemic, of not yielding to individualism; the hope is that a focus on common interests will give priority to those in need of help. The ethical framework then identifies values that also play an important role in an emergency: respect for individual freedom, proportionality, respect for privacy and for equity, as well as the importance of trust between the population and the authorities. Proportionality means in this case that the harshness of any public health measure must be proportional to the anticipated risk involved. Regarding equity, it seeks to establish the equality of each citizen, and to deny any privilege stemming from an individual's economic or social status. Beyond these principles and values, the Swiss plan details a number of rules for the allocation of resources; the rules change according to the level of the alert, the individual's state of health and their role in the implementation of any plans (medical personnel for example) (Office Fédéral de la Santé Publique, 2006).

The New Zealand ethical framework simply lists the values for the decision process and content in the event of a pandemic. According to the characteristics defined in the plan, the decision making process must be open, inclusive, reasonable, responsive and responsible. In addition, decisions must be based on the minimization of harm, fairness, respect, neighbourliness, reciprocity and unity. Also, it is interesting to note that the inclusion in the New Zealand plan of more communitarian values such as neighbourliness and unity is the result of consultations with indigenous groups in that country (Ministry of Health, 2006).

Overall, it is important to note that, even in these three plans, which are remarkable in many aspects, public participation *is not* considered an ethical issue or a moral obligation as such.

Public Participation

Following the general structure for plans as outlined in the WHO checklist, the relationship between experts and the lay public is first of all established through communication strategies, the fundamental objective being to inform the public and to facilitate its contribution in a collective endeavour to protect public health in the event of an influenza pandemic. In order to ensure effective implementation of the plans, a number of values are also associated with communication strategies. Most of the plans place the emphasis on the necessity of creating and maintaining

the people's confidence, firstly by transparency in the decision making process, and secondly, through accessibility, the timeliness of transmission, and the relevance of the information. In heavily populated countries such as Korea, Vietnam or Thailand, where the population is dense and the risk of a pandemic is possibly higher, their plans also insist on the importance of creating, by means of a strategy of adequate communication, an environment favourable to a politically stable State (Bureau of General Communicable Diseases, 2005) (Ministry of Agriculture and Rural Development and Ministry of Health, 2006) (Korea Centers for Disease Control & Prevention, 2006). A great majority of the plans have thus envisaged *unidirectional* communication strategies (Rowe & Frewer, 2005, 251-290) (Doucet, 2002) in which the citizen is perceived above all as having a subordinate role, or simply as a vector of the illness that must be 'controlled' in order to reduce the risks of the pandemic.

However two plans are exceptions to this trend. They propose alternative models for consultation and even for public participation, the assumption being that this would facilitate the functioning and flexibility of public health measures. Thus, the United Kingdom's plan describes three creative models of *bi-directional* communication with the population which are included in a wider strategy for information about the levels of pandemic risk (UK Health Department, 2005). The first of these models calls for *focus groups* and *NHS Direct on-line,* where citizens can ask questions and express their concerns. This tool is therefore not merely informative, but also consultative; it facilitates feedback, which enables those in charge to adapt their response to what they hear from citizens.

The second mechanism proposed by the British plan goes somewhat beyond consultation, since it suggests a type of participation in the decision making process. Indeed, the plan foresees the formation of *expert advisory groups,* composed of members of the public charged with advising the authorities on measures to take in the event of a pandemic alert.

The third mechanism is somewhat different in that it is comprised only of experts; there are no lay citizens involved, strictly speaking. However these experts are not drawn solely from those responsible for the functioning of the plans. Instead they come from the media, and are brought together in a body called the *regional media emergency forum*. This body includes experts recruited from all the spheres of communication (the media, government, public safety, hospitals, etc.). Its objective is to organize the channels of communication as efficiently as possible, should an emergency situation occur.

The Brazilian plan only indicates that those in charge must conduct a public consultation in order to develop public policies for emergency care in the event of a pandemic alert. Although the method is unspecified in the plan, the public is called on to play an active role alongside the decision makers in establishing priorities for the allocation of certain resources, such as beds (Health Surveillance Secretary, 2005). Like the British plan, the Brazilian plan goes beyond simply providing information, since it foresees a role for *consultation* and *participation* fulfilled by the citizens affected by an influenza pandemic. It is interesting to note that, regarding public participation, the situation in Brazil is almost unique. In article 198 of the most recent Brazilian constitution of 1988, referring to social order, there is, for government authorities, including public health policy-makers, a constitutional obligation to involve the community in the decision-making process.[2]

THE PUBLIC'S ROLE IN THE PLANS:
A DIFFERENT PERSPECTIVE FOR PUBLIC HEALTH

Contribution to More Effective Management

Effective public health strategies must be able to rely on well-founded knowledge of the frequency, distribution, determinants and consequences of illnesses, whilst at the same time carefully evaluating the level of effectiveness and the security of any interventions (Victora, Habicht & Bryce, 2004, 400-405). Some experts believe, however, that to reach this goal of developing, managing and using exact scientific knowledge in public health, *lay* knowledge is too often neglected and underestimated (Watkins, 2002, 160-164) (Little, 1998, 1135-1145). It must not be forgotten that the public is an *agent* of public health, to the extent that nothing is possible in terms of prevention, protection or promotion of health without citizen collaboration. It is all the more true that coercive or paternalistic interventions are generally contrary to the values of freedom and the promotion of individual rights in liberal societies. One can also consider the public to be a *witness* in public health, since public health problems tend to arise in areas inhabited by those who are the first to

[2] See the Constitution of Brazil translated into English. Available at: http://www.v-brazil.com/government/laws/titleVIII.html [accessed 22 May 2008].

be affected and the first to perceive the consequences of the problems. Thus mechanisms putting in place by which communities – including the community of health care providers – can discuss and explain their precise needs can only facilitate the development of more appropriate measures (Mann, 1997, 6-13). Regarding the preparedness for pandemic influenza, much has been said about the social distancing that is likely to take place to prevent the virus transmission. But even the most detailed plans cannot predict the consequences of some restrictions without the close collaboration of those working on the ground. For instance, what if we close elementary schools, leave the kids at home and force their parents to temporarily quit their jobs? In attempting to solve a problem, will the authorities be creating much more complex obstacles? In this case and in many others as well, public involvement could be of great help in *thinking outside the box* and avoiding unexpected problems. Finally, the public is also the *embodiment of values* in a society, and it is, in part, these values that define the sense of wellbeing in communities. This aspect of society, as a component of our concept of health, must not be ignored by the public health authorities. Yet, in all plans, risk assessment is based mainly on epidemiological (e.g. pathogenicity) and statistical data (e.g. spatio-temporal disease mapping). This positivist epistemological approach tends to ignore that the notions of *risk*, *disease* or *appropriate* intervention may be quite diverse in societies with different cultural and socio-economic backgrounds. Consequently, it might be advisable to adopt asymmetrical information and communication strategies that are in step with the plurality in which we are living. The experts were probably aware of the problem, but it did not emerge from the analysis. Instead the decision making process is almost exclusively built on science and leaves little to the social construction of public health.

As expressed in the *Ottawa Charter for Health Promotion*, ideally public health:

> works through concrete and effective community action in setting priorities, making decisions, planning strategies and implementing them to achieve better health. At the heart of this process is the empowerment of communities - their ownership and control of their own endeavours and destinies. Community development draws on existing human and material resources in the community to enhance self-help and social support, and to develop flexible systems for strengthening public participation in and direction of health matters. (WHO, 1986)

But most of the plans base their interventions on a *top-down* approach which is supposedly justified by the necessity of emergency procedures and by the international structure of the response to pandemic influenza (the WHO has the responsibility to declare the phase of the pandemics). But what is usually ineffective and ethically inappropriate in public health does not automatically become more effective and appropriate during emergencies. The flexibility required by complex situations created through pandemics should foster the implementation of a *bottom-up* infrastructure that will complement the *top-down* approach. This objective could be reached through the integration of citizen-expert advisory boards into the global response to pandemics (see UK plan). Unfortunately, very few parts of the national plans expound the benefits of a strategy founded on this kind of complementary approach.

Another way to increase public involvement and to improve response effectiveness might involve integrating some principles of *civil security* into pandemic plans. The principles of civil security used in many countries encompass partnerships and *shared* responsibility with local communities, the private sector and, above all, with the population in general. The key components of any civil security programme are (for each person individually): 1) hazard identification; 2) preventive measures (i.e. personal hygiene); 3) solidarity within the community. These principles are rooted in a logic of public participation as they implicitly recognize the collective capacity that lay people have to take greater control of their destiny.

Ethical Justification

Within the ethical frameworks applicable to a pandemic influenza found in the national plans, or in the professional literature focused on the ethical challenges related to pandemic influenza (Pandemic Influenza Working Group, 2005; Gostin, 2006, 1700-1704), there is recognition of the notion that respect for autonomy and for the dignity of persons must continue to be a pre-eminent value. If this is so, one might inquire whether or not respect for autonomy and dignity must logically imply the shaping of mechanisms in which citizen discourse (an essential extension of this autonomy and dignity) can be expressed and have an influence on the development of interventions intended for citizens. In fact, even if, under certain circumstances, these interventions could effectively undermine personal integrity and freedom, the fact remains that respect for autonomy

is not fulfilled solely by a *reduction* of coercive measures (a negative view of autonomy). Above all, respect for autonomy is realized when active participation in public health efforts leads citizens to *responsible action* (a positive view of autonomy) (Mann, 1997). By taking citizen discourse into account, a situation where the population is manipulated for purely bureaucratic purposes can be avoided.

Moreover, one must assess whether bidirectional mechanisms for the exchange of information between citizens and experts would support the values of transparency and confidence endorsed in the communication strategies of the different plans. It is not unusual to hear it said that, in an emergency, it becomes difficult, if not useless, to consult the populace, since it is important to act, and to act quickly. However, beyond the advantages that could be characterized as operational, noted earlier, there is a tendency to underestimate the almost *cathartic* effect of listening to the views of the public. Indeed, when given the opportunity to express their fears and concerns people can *cool down* and still be able to think on their feet. So, it is fair to assert that transparency on the part of decision makers helps to gain the public's confidence. However it can be difficult to convince the populace to put aside its mistrust if the authorities rely solely on *formatted* communication strategies. As a matter of fact, this kind of mistrust toward experts and political authorities has been a real problem during the H1N1 influenza pandemic. Bidirectional approaches that seek public participation can thus reinforce this necessary bond of trust and, at the same time, promote, on the part of decision makers and experts, a form of *social responsibility* that acknowledges the capacity of the populace to make enlightened choices (Ethics Subcommittee of the Advisory Committee to the Director, Centers For Disease Control And Prevention, 2007; The Public Engagement Pilot Project On Pandemic Influenza. Citizen Voices On Pandemic Flu Choices. Lincoln, 2005). Also, from a normative point of view, the experts should keep in mind that *social acceptability* is a powerful means of justification in law and ethics (Aamio, 1986). In that sense the autonomy developed through public engagement respects the tradition and ideal of liberal societies, which reinforces the cohesion of the public health response to pandemics. Finally, in a general way and an almost Kantian view, public participation can encourage decision makers to ethically 'universalize' the decision making process, in other words, to put aside particular institutional interests in favour of a common vision supported by a diverse citizen discourse.

CONCLUSION

In the unique and critical context of preparing for an influenza pandemic, the management of risks and consequences becomes a delicate task, for which errors can become very costly, both for humans and for the economy. Well beyond its traditional goals of preventing illness or promoting health, public health has become necessary to preserve the economic and social integrity of nations. This calls for the difficult creation of a negotiated balance between differing interests, expectations and understandings, which simultaneously hold together and fragment the foundations of society. In this context, public participation promotes such a balance through the goodwill and dialogue it fosters amongst decision makers, experts and the general population. For these reasons one must consider public participation as an issue of increasing importance. This is especially the case given that public health is evolving towards the integration of targeted interventions that, with the help of biotechnologies such as genomics, could initiate a transformation of the *one size fits all* paradigm. Consequently, the perspective of using a wide range of personal data *for the sake of common good* is bringing out new issues that are not solely political or economic. Therefore, it becomes necessary to adopt a prospective approach, for the future management of public health emergencies, which includes the views of the lay public. Thus, beyond its role in ethical justification, mentioned previously, public participation becomes an important element in many global issues, linked as much to questions of health and education as to the imperatives of good governance, the decentralizing of decisional powers and the empowerment of communities (André, 2006).

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