

# The Return of Quarantinism and How to Keep It in Check: From Wishful Regulations to Political Accountability

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## Abstract

Concerns about emerging and re-emerging infectious diseases have given a new lease of life to quarantinist measures: a series of time-honoured techniques for controlling the spread of infectious diseases through breaking the chain of human contagion. Since such measures typically infringe individual rights or privacy their use is subject to legal regulations and gives rise to ethical and political worries and suspicions. Yet in some circumstances they can be very effective. After considering some case studies that show how epidemics are unique, fluid and affected by a multitude of contingent factors, it is argued that the legal and ethical guidelines may not always be the best approach to discipline the use of quarantinist measures. An alternative model based on ex-post political accountability for reasonableness is proposed. This model restores the centrality of political decision and expert judgement in situations characterized by high risk, uncertainty and contingency. It is argued that such alternative model affords quicker and more flexible responses to serious outbreaks of infections, while providing adequate protection against abuses.

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## List of Abbreviations

QM: quarantinist measure	SARS: severe acute respiratory syndrome
WHO: World Health Organisation	ID: infectious disease
AIDS: acquired immunodeficiency syndrome	PH: public health
HIV: human immunodeficiency virus	STD: sexually transmitted disease
TB: tuberculosis	DOT: directly observed therapy

## Introduction

*“When we give some persons power in our society (as we must),  
and appoint others to watch them (as we’d better),  
who is going to watch the watchers?  
Can we really stand a society in which everybody watches everybody?”*

(Robert M. Adams)

This paper explores the problems raised by the use of quarantinist measures (henceforth QMs), i.e. those strategies for stopping or containing contagion by breaking the chain of transmission. They include quarantine, isolation, compulsory vaccination, testing or treatment, sequestration and destruction of goods or livestock, notification and contact tracing. These measures have a long history, but in developed countries their use has declined following the epidemiological transition and the decline of infectious diseases (henceforth IDs) as a cause of mortality. Yet, in the last three decades they have come back into the public health agenda as a consequence of a renewed concern for the threat of new and re-emerging IDs. A problematic feature of such measures is that they typically infringe individual liberties or violate privacy and confidentiality, therefore there is growing interest in their regulation and in regulating their use so as to minimize interferences with individual liberties and rights.

The trend so far has been to develop ethical guidelines and legal regulations to minimize the risk of abuse of QMs. My aim is to question whether this approach is the only possible and the best strategy to keep the use of QMs under control. I claim that the issue deserves to be explored further and that the ethical and legal points of view that have dominated the discussion so far need to be integrated by the contribution of political theory.

I begin by illustrating the historical and biological context that has brought contagious diseases back to the public health agenda. I then explain why QMs cause concern and how these concerns spring from essential tensions within public health and liberal-democratic

thought. I then turn to three important case studies that illustrate very vividly the empirical—but also some theoretical—difficulties in both handling and regulating QMs. I begin with the more recent case, SARS, and then I move backward to the epidemic of TB in New York City in the 1990s, and I finish with the most discussed epidemic of our times: HIV/AIDS. The last case study, through the discussion of the so-called AIDS exceptionalism, provides a good introduction to the final theoretical discussion, in which I outline an alternative model for keeping the use of QMs under check. I propose a particularist approach as an alternative to formulaic legal regulations which are not sufficiently context-sensitive to render emergency public health interventions effective. More leeway is granted to political and technical decisions, within a framework that aims at securing *accountability for reasonableness*. The hope is that the model may be at once more flexible in responding to the uniqueness of each contagious disease, and leave more room for political decision and democratic activism.

### **The Return of Infectious Diseases**

*“Ingenuity, knowledge, and organization alter  
but cannot cancel humanity's vulnerability  
to invasion by parasitic forms of life.*

*Infectious diseases which antedated the emergence  
of humankind will last as long as humanity itself”*

(William McNeill)

From the moment humankind abandoned the nomadic lifestyle of hunters and gatherers and began to cultivate the land, rear livestock and found populous cities, infectious diseases have been a main scourge of humanity and the major cause of mortality. Domesticating animals has exposed humans to an impressive number of zoonoses, while agriculture has made

possible surplus production that in turn could sustain much higher population density and intensified trade. These socio-economic changes enabled pathogenic microbes to establish either lasting chains of transmission within a large enough community (endemic infections), or very long and unbroken paths of contagion (epidemics). Unsurprisingly endemic diseases settled in densely populated areas, while epidemics typically spread along commercial routes (McNeill 1977; Karlen 1995). In spite of their ingenuity, human beings made only modest advances in the understanding and control of contagious diseases until well into the 19<sup>th</sup> century. Inoculation began to deliver some encouraging results in the 18<sup>th</sup> century, while improved nutrition and hygiene contributed to lower the death rate from the middle of the 19<sup>th</sup> century. The first great breakthrough in the understanding of infectious diseases only arrived towards the end of the 19<sup>th</sup> century thanks to the discoveries of Pasteur and Koch and the birth of bacteriology (germ theory of disease). Yet, in spite of its theoretical significance (and its importance in grounding preventive strategies on sound scientific bases) bacteriology did not produce immediate therapeutic benefits. Those only arrived with the discovery of sulphonamides in the 1930s and with the development of antibiotics in the 1940s. By that time infectious diseases were already on a steady and long-term path of decline in industrialized countries, so that the new drugs, together with new vaccines, led to further successes and to an age of great optimism about the prospect of leaving infectious diseases behind. The acme of this series of successes and of their accompanying optimism was reached at the end of the 1970s when a vigorous world campaign led by the WHO and supported by both the USA and the USSR led to the eradication of smallpox.

There is some irony in the fact that the year after the eradication of smallpox the first cases of what would be later known as HIV/AIDS came to the attention of the Centre for Disease Control (CDC) in the United States. The step from the most spectacular success in the fight against infectious diseases to the appearance of the major pandemic of the second half of the 20<sup>th</sup> century represents a watershed: from an age of optimism to an age of renewed concern about IDs (Gregory 1998: 547; Whitman 2000a: 1; Battin et al. 2009: 3). To be sure, AIDS

was not the first new ID to gain attention and cause alarm. In the previous decade, for instance, worries were caused by Ebola, Lyme and Legionnaire diseases, but none of them caused any major outbreak in developed countries (although Lyme has become endemic in North America and parts of Europe). More significant was the impact of toxic shock syndrome, but the virus responsible for it and an effective prophylaxis were soon discovered. What is now clear is that IDs are by no means a relic of the past, confined to tropical underdeveloped areas or to marginal ecological niches.

Anyway, let us not forget that this story of triumphalism followed by renewed concern is very parochial and reflects the point of view of wealthy countries, while in most of the world IDs have never ceased to be a major threat and a leading cause of mortality and morbidity. According to the last WHO data, infectious and parasitic diseases are responsible for between  $\frac{1}{4}$  and  $\frac{1}{3}$  of all deaths in lower income countries, while they still cause around  $\frac{1}{10}$  of deaths in upper medium income countries. Only in wealthier countries is their death toll much lower: around 2% (WHO Global Health Observatory). Hence the burden of IDs is still a major concern in developing countries, and it is important to keep in mind that the story I have sketched so far does not express a global perspective.

Concern about the return of infectious diseases has two different dimensions that are often treated together, but which benefit from being separated, for they present important differences. The first leg of the problem is represented by **emergent** infectious diseases: these are conditions that have only been identified and recorded in recent decades, i.e. threats that were not known before—although it cannot be excluded that some of them had occasionally infected some isolated group of human beings. If we put them together, the list of new and emerging diseases recorded since the early 1950s is rather long and frightening (see the lists provided in WHO 1998; Lederberg 2001: 15; Karlen 1995: 8), but we should avoid glib sensationalism. The high number of newly discovered infectious diseases is in part the consequence of our increased scientific ability to isolate pathogens and distinguish accurately between ailments with similar symptoms—for instance there is a broad variety of

haemorrhagic fevers (e.g. Korean, Dengue, Venezuelan, Bolivian, Lassa, Ebola etc.).

Furthermore, it is also likely that the length of the list is the effect of the present worldwide web of surveillance that can quickly react to and record the emergence of new diseases. The result is that some of the diseases that are listed as emerging are not *newly emerged* diseases, but *newly recognized* diseases. Finally, it is important to keep in mind that the greater part of those diseases are still rarities and have not caused large numbers of casualties, let alone had any significant demographic impact. Yet other diseases have had a serious impact and have established themselves as endemic in certain areas (e.g. Dengue fever, Lyme disease, Lassa fever) or caused serious outbreaks (e.g. Venezuelan haemorrhagic fever, *Escherichia coli* 0157:H7) and one has caused an extremely serious pandemic: HIV/AIDS.

The other leg of the problem is represented by **re-emergent** (or resurgent) diseases, i.e. diseases that are increasing their prevalence and diffusion. The reasons for re-emergence are varied. They range from the emergence of new strains of microbes—in particular drug-resistant strains, such as multi- or extreme-drug resistant TB—to the larger diffusion of their vectors—for instance because of climate change, as in the case of Dengue fever—to the breakdown of public health structures and preventive strategies—as it has happened most notably (but not exclusively) in former communist countries of central and eastern Europe (Garrett 2000). If we exclude AIDS, from an epidemiological point of view, re-emergent infectious diseases have had a much greater demographic impact and are causing serious alarm; for instance TB was declared a global emergency by the WHO in 1993 and is the ID responsible for the highest number of deaths in the world today (estimates range between 1,5 to 3 million a year).

What is worrying about emerging and resurgent IDs is the fact that the causes of such phenomena seem to be integral parts of the contemporary world economy and lifestyle, so that it does not seem likely that patterns of emergence and resurgence can be stopped or

reversed in the near future. In 1992, the Institute of Medicine (IOM) listed the following factors in Infectious Disease Emergence and Re-emergence:

- Increased human intrusion in tropical forests
- Lack of access to health care
- Population growth and change in demographics
- Changes in human behaviour
- Inadequate and deteriorating public health infrastructure
- Misuse of antibiotics and other antimicrobial drugs
- Microbial adaptation
- Urbanization and crowding
- Modern travel
- Increased trade and increased markets for imported foods<sup>1</sup>

And in 2003 they added:

- Climate and weather alterations
- Changing ecosystems
- Economic development and land use
- Poverty and social inequality
- War and famine
- Lack of political will
- Intent to harm<sup>2</sup>.

It seems therefore clear that in spite of all our scientific and medical advances our present modes of production and life are going to offer considerable opportunities to infectious diseases and that the latter are going to be an enduring major cause of concern, mortality and morbidity.

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<sup>1</sup> Quoted in Lederberg, *op.cit.*, p. 7.

<sup>2</sup> Quoted in Fidler, David P., *SARS, Governance and the Globalization of Disease*, Palgrave Macmillan, Basingstoke and New York, 2004, p. 181.

## The Return of Quarantinism

*“Si l’État est fort, il nous écrase.*

*S’il est faible, nous périssons”*

(Paul Valéry)

This lasting vulnerability and exposure to old and new infectious diseases has brought back to attention the traditional public health measures to tackle and contain the spread of contagion, among which QMs are preeminent. In spite of having often been described as anachronistic, they seem to be far from being granted retirement as is well illustrated by the recent decision of the USA to more than double their quarantine stations<sup>3</sup>, and also by the revised International Health Regulations issued in 2005, in which (sub article 18), a list of recommendations that the WHO can issue to states includes the following QMs:

- require vaccination or other prophylaxis;
- place suspect persons under public health observation;
- implement quarantine or other health measures for suspect persons;
- implement isolation and treatment where necessary of affected persons;
- implement tracing of contacts of suspect or affected persons;
- refuse entry of suspect and affected persons;
- refuse entry of unaffected persons to affected areas;
- and implement exit screening and/or restrictions on persons from affected areas<sup>4</sup>.

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<sup>3</sup> CDC, History of Quarantine.

<http://www.cdc.gov/quarantine/HistoryQuarantine.html>

Accessed on 06/07/2010

<sup>4</sup> WHO, Revision of the International Health Regulations (2005).

[http://apps.who.int/gb/ebwha/pdf\\_files/WHA58/WHA58\\_3-en.pdf](http://apps.who.int/gb/ebwha/pdf_files/WHA58/WHA58_3-en.pdf)

Accessed on 24/08/2010

Liked or loathed, QMs are back to stay, hence it is important to understand why the powers to use QMs are both feared and valued.

The reasons why QMs raise concerns and suspicion are easy to explain: they often infringe individual liberties or violate privacy and confidentiality, and since freedom and privacy are highly valued, it cannot come as a surprise that QMs meet with hostility.

These worries about freedom and privacy are particularly acute in an age like ours, that on the one hand celebrates individuality, originality and self-expression, but on the other hand increasingly sacrifices the scope of these values on the altar of rationality, security, efficiency and standardization. Moreover, biomedicine has enabled the health care system to penetrate the secrets of our bodies and even of our individuality (genetics) and can now store them through information technologies that are as powerful as they are vulnerable to abuses and cyber-piracy. The intimate secrets of our bodies can be captured more deeply and communicated more quickly than ever before. As a result, the most intimate and personal aspects of our lives can be used to our detriment—e.g. to foster prejudices or to deny access to opportunities and resources.

Finally, worries emerge also when we look at the issue not from the perspective of infected or potentially infectious people, but from the point of view of public health authorities. There are good reasons to be worried about granting quarantine powers to officials. The early history of medical police and its connection with absolutism in politics and with the desire to control and regiment the population in the interest of rulers and state power contributes to feeding suspicion (Rosen 1953; Price-Smith 2009: 194-6). By analogy, abuses of exceptional war powers even in well-established democratic regimes suggest that reluctance and caution in granting special powers and suspending legal protection are but a matter of prudence (Linfield 1990). Lastly, the history of QMs is not lacking in examples of uses prompted by racial or national prejudices, or by social hostility for disliked groups—even the USA, a democratic, multiethnic nation of immigrants provides several example of discriminatory

uses of quarantines, for instance against Chinese, Jews or Haitians (Sherman 2006: 128-31; Harrison 2004: 138-42; Annas 1993).

All the above suspicions are perfectly understandable and not without justifications, but now we need to have a look at the other side in order to understand why QMs are also valued as potentially precious tools of prevention and containment. The historical record of QMs does not provide unambiguous evidence for or against their effectiveness (Ackernecht 1948; Cipolla 1976; Musto 1986; Baldwin 1999; Watts 2003; Harrison 2004; Sherman 2006; Hamlin 2009). From a biomedical point of view, it is hard to deny that in principle the range of QMs do make sense at least for diseases that are transmitted from human to human.

Preventing infected people from infecting others and trying to reach people who have (or may have) been exposed to contagion are by no means meaningless or valueless principles. Germ theory provided a generic rationale for QMs, although the practical value of each measure depends on the particular aetiology, infectiousness and geo-epidemiology of each disease. Recently, QMs have proved successful in the containment of SARS and other outbreaks; they have been successfully used in bringing under control the epidemic of TB in New York City and arguably have delivered significant results in the curtailment of the AIDS epidemic in Cuba.

It is not surprising therefore that those who look at QMs from the point of view of individual rights and freedom tend to be worried about them, while physicians and PH officials value them as a useful tool, that should not be discarded out of ideological prejudices.

The conflict between public health and individual rights has long been recognized. An early example of a strong and successful reaction against public health measures in the name of civil liberties can be found as far back as the early 18th century, when public protest in England led to the reform of the harsh Quarantine Act of 1721, considered incompatible with “English freedom” (Baldwin 1999: 562). “Disease control measures invade each of the major spheres of personal liberty” (Gostin 2003: 1107; cf. Wilkinson 2009: 181; Bayer 1986: 172;

Bayer 2007: 1099; Parmet 2003: 1222. For the opposite view see Mann 1996-7: 204; Annas 2007: 1093 and 1097. See also Oppenheimer, Bayer & Colgrove 2002), since protecting the health of the public requires restricting behaviour and movement, imposing treatments or vaccinations, extracting and disclosing personal information, sequestering and destroying properties or livestock. The tension between public health and individual freedom is not limited to the control of IDs, but is equally common in attempts to secure environmental safety and to prevent accidents and injuries. Imposing helmets on motorcyclists or construction workers, closing city centres to traffic, screening women for breast cancer, testing car drivers for alcohol or drugs, these are all activities that make perfect sense from the point of view of public health and yet may be perceived as encroaching on personal freedom and privacy.

The tension between individual rights and public health is rooted in a conflict within Western political thought that has perhaps been stated most clearly and eloquently by Benjamin Constant in his famous 1816 essay on *The liberty of the ancients compared to that of the moderns* (Constant 1988). Constant pointed out that there is an irreconcilable tension between preserving a sphere of private liberty—within which individuals are free from governmental and societal interference and able to conduct their affairs as they please—and empowering the citizenry to enact the policies and regulations that it considers necessary in order to promote their common good and shared goals. In short, Constant puts in stark relief the contrast between the liberal and the democratic views of liberty. The former is sceptical, defensive and negative, preoccupied with setting boundaries and constraints to political power; the latter is hopeful, proactive and positive in its attempt to empower the democratic community with the instruments to promote its welfare and act together to achieve its goals. The former wants to avoid tyrannical oppression and arbitrary domination. The latter wants to enable the people to solve problems of public choice and collective action. To use a

medical metaphor, the former is worried by the pathologies of political power, while the latter is interested in the therapeutic virtues of political power<sup>5</sup>.

The conflict between public health and individual rights is just a particular instance of this general tension that lies at the heart of Western political thought and of its most successful product: liberal democracy. This tension is not purely theoretical, but is also reflected in the political life and institutional arrangements of western democracies. For instance in an important study James Morone has argued that the political tradition of the USA is characterized by two conflicting trends: on the one hand Americans are highly suspicious of governmental power and have posed very strong limits to it in their constitution; on the other hand there is a persistent longing for popular government, for a real involvement of the people in the life of the nation. According to Morone, many key moments and movements in American political history can be understood through the dialectic between conservative liberalism and idealistic democratic impulses. This means that the actual institutions, governmental agencies and bureaucracies have been shaped by this tension<sup>6</sup>.

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<sup>5</sup> John Stuart Mill's *On Liberty* is perhaps still the most clear and influential statement of the liberal view. John Knowles's "The Responsibility of the Individual" (*Daedalus* 106(1), 1977, pp. 57-80) expresses most effectively the dissatisfaction with a liberal-individualistic approach in health ("one man's freedom in health is another man's shackle in taxes and insurance premiums. I believe the idea of a 'right' to health should be replaced by the idea of an individual moral obligation to preserve one's own health—a public duty if you will", p. 59), yet Knowles cannot go as far as to advocate the backing of the law to enforce the duty to preserve one's health. It is as if he strongly advocates the democratic end of the common good without endorsing the democratic means of legislating for achieving it. Characteristically he invokes education (this preferred liberal means), rather than legal enforcement, as the means to achieve the recommended end. In this combination of democratic ends and liberal means Knowles provides an effective example of how the tension between democracy and liberalism affects thinking about health policy.

<sup>6</sup> Morone, James A., *The Democratic Wish. Popular Participation and the Limits of American Government. Revised Edition*, Yale University Press, New Haven and London, 1998 (first edition, Basic Books, 1990).

In the USA this tension is also reflected in frictions between the government and the Supreme Court, where the former is seen as the legitimate expression of the will of the majority, while the second is seen as the custodian of citizens' rights. But similar conflicts and oppositions can be seen in Europe as well. Recently the most discussed example is provided by tensions between the European Union and its member states. The EU often produces laws and regulations that protect important freedoms and rights and have higher standards than national legislation, nonetheless the EU is seen with suspicion as too distant and bureaucratic an institution, lacking both democratic accountability and the ability to reflect a shared national identity and command allegiance. The result is that European citizens are happy to use Communitarian legislation and rights against their own states, but at the same time have so far resisted any decisive transfer of sovereignty to the European level, most notably through the Dutch and French referenda that sunk the EU constitution.

The above mentioned examples show that the opposition between democratic will (the liberty of the ancients) and liberal rights (the liberty of the moderns) is at the core of our political life and feelings. Moreover, it is also at the core of the case studies to which we now turn, for disputes around QMs always revolve around this tension.

### **The SARS outbreak**

*“Each new generation is presented with new problems and new challenges, and analogies drawn from the past are likely to be more of a hindrance than a help in solving them.*

*If the past has anything to teach us it is humility  
—and suspicion of glib formulae for improving the lot of mankind”*

(Michael Howard)

Severe Acute Respiratory Syndrome (SARS) emerged in November 2002 in the Chinese province of Guandong, but the local Chinese authorities did not report the outbreak to the

WHO. It was only in March 2003 that Carlo Urbani—an Italian physician working in Vietnam—alerted the WHO of the presence of a new infection. The international health authorities immediately started the hunt for the pathogen and, as soon as they tracked its origin in Hong Kong, they realized that this densely populated metropolis and principal airways hub of Asia was the ideal springboard for a global pandemic. Given that the disease had already proven deadly in several cases and rather infectious as well—a number of doctors and nurses who treated the first patients were among the early victims—the emergency plan was immediately acted upon. Contact-tracing proved decisive in order to reconstruct the chain of contagion and the origin of the infection. It turned out that several patients had a link with the 9<sup>th</sup> floor of the Metropole Hotel in Hong Kong. This piece of information indicated that while the disease was easily communicable it was not as highly contagious as, say, smallpox. Presumably the contagion spread through droplets and through faeces. It later emerged that it was caused by a pathogen of the Corona virus family, for which there are no cures<sup>7</sup>. At this point the outbreak had all the features to call for the deployment of most QMs—including isolation and quarantine:

1) high mortality rate (at the end of the epidemic it turned out to be just below 10%), 2) absence of a cure or vaccine, 3) a mode of communication which is contagious enough to make casual contact quite dangerous, but not so highly contagious as to make the isolation of patients and quarantine of contacts hopelessly inadequate to stop the spread of disease, 4) a still limited number of cases concentrated in a few *foci*. With such a profile, isolation and quarantine are feasible if public health authorities act promptly and efficiently and there is reasonable hope that they may succeed. After the early inertia and lack of openness of the Chinese reaction, as soon as the WHO sounded the alarm, the health authorities of the

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<sup>7</sup> Baker, Robert, *Quiet Killers. The Fall and Rise of Deadly Diseases*, Sutton Publishing, Stroud UK, 2007, pp. 184-9; Crawford, Dorothy H, *Deadly Companions. How Microbes Shaped our History*, Oxford University Press, Oxford, 2007, pp. 1-7; for a more detailed reconstruction see Fidler, *op. cit.*

countries affected by the epidemic produced a sustained effort to isolate, quarantine, trace contacts and in some cases used the threat of severe punishment—up to the death penalty in China—or high-tech surveillance techniques—cameras and electronic bracelets in Singapore<sup>8</sup>. The response succeeded and by July 2003 the epidemic was under control and soon abated.

Since March 2003, the drama of the SARS epidemic unfolded under the close scrutiny and extensive coverage of the media. As a result, the event had major public visibility and symbolic value. What the global public saw was a dangerous infectious disease quickly spreading to several countries, where it infected thousands and killed hundreds before being successfully controlled under the leadership of the WHO and through the consistent use of QMs by the nations hit by the epidemic. It may well look like a good advertisement for QMs right at the beginning of the century; could it also be a sort of keynote event for public health? There is evidence that this experience has contributed to make QMs look more scientifically respectable and less politically alarming. On the other hand, though, things are not so straightforward and the small number of quarantined people who have developed the disease has been read as evidence that there was an over-reaction. This is particularly true in the case of Taiwan, where 131,132 people were subject to quarantine and there were among them only 2 cases of confirmed infections. Taiwanese authorities themselves later admitted that their use of quarantine was exaggerated and probably counterproductive, for it generated panic<sup>9</sup>.

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<sup>8</sup> Mitka, Mike, “SARS Thrusts Quarantine into the Limelight”, *JAMA* 290/13, 2003, pp. 1696-8.

<sup>9</sup> Rothstein, Mark A. *et alii*, “Quarantine and Isolation: Lessons Learned from SARS. A Report to the Centers for Disease Control and Prevention”, 2003, pp. 9 and 131

[http://www.iaclea.org/members/pdfs/SARS\\_REPORT.Rothstein.pdf](http://www.iaclea.org/members/pdfs/SARS_REPORT.Rothstein.pdf)

Accessed: 25/08/2010.

In my view, what the SARS case really shows is that while it is possible to learn some useful lessons about the challenges to the effective implementation of QMs and to the kind of preparedness that is required, **no normative rule on the use of QMs can be inferred**. While the SARS episode has an important symbolic effect that contributes to a trend of increasing reevaluation and acceptance of QMs, it also shows that their justification and effective implementation are influenced by numerous contingencies and uncertainties, so that any attempt at strictly regulating and disciplining their use in advance is misguided. I am not saying that there are no sensible ethical and legal rules that indicate fair procedures in the implementation of QMs. Several examples of such rules have been proposed (see for instance Gostin, Bayer and Fairchild 2003, Ries 2004). My contention is that in typical emergency circumstances following all these rules may be neither possible nor wise. The most we can demand is full transparency and openness, and to be given a convincing rationale for violations. Regulations and guidelines hence are more a roadmap of ethical desiderata, than strict protocols.

Let me expand on the previous points, beginning with the symbolic and cultural impact of the epidemic and its containment. During the outbreak scepticism towards QMs was still common; Joseph Barbera, co-director of the Institute for Disaster and Risk Management at George Washington University could still declare boldly “When you look carefully at quarantine history, it was always a failure” (quoted in Mandavili 2003: 487). But as the epidemic was brought under control, the fundamental role played by QMs became widely acknowledged and those time-honoured measures even began to assume a reassuring character, for they seemed relatively simple and able to work even when science could not help us. For instance, Bradsher and Altman in an article that appeared in the liberal New York Times wrote:

Reassuringly, SARS appears to have been controlled mainly through one of the oldest of medical tools: isolation (Bradsher and Altman 2003).

In a book entirely devoted to the significance of SARS for public health and politics, David Fidler confirms that the “public health instruments at the forefront of the SARS battle were surveillance, isolation, and quarantine” (Fidler 2004: 106). Similarly the WHO claimed that QMs had played a decisive role in overcoming the epidemic and such a conclusion was, according to Gostin, Bayer and Fairchild, “Beyond question” (Gostin, Bayer and Fairchild 2003: 3231). The authors of two recent books on infectious disease fully endorse the view that QMs were decisive in stopping the SARS epidemic, indeed one of them—Stefan Kaufmann director of the Max Planck Institute for Infection Biology in Berlin—endorses quarantines wholeheartedly (Crawford 2007: 4-5; Kaufmann 2009: 113, 146, 154). It is remarkable that even prestigious academics pursuing a global justice agenda—like Kaufmann—do not feel embarrassed or apologetic in advocating the use of quarantines. It is hard to resist the impression that the success in bringing SARS under control has contributed significantly to making QMs scientifically more respectable and ethically more acceptable. To be sure this does not mean that there is general agreement on the utility and justification of quarantines, some scholars, like George Annas, believe that quarantines were unnecessary and even dangerous in the management of SARS (Annas 2007: 1095-6).

From a social and cultural point of view the SARS episode represents another step in a trend that moves towards a reevaluation of QMs. In 2003 the WHO attitudes towards QMs has been significantly different from its recommendations in the 1970s when the emphasis was much more on a sanitation and environmental approach and quarantines were dismissed (Hamlin 2009: 287). The SARS episode built on a slow but steady trend towards a less negative view of QMs that began—as I will demonstrate in the next sections—with the reaction against radical anti-quarantinism in the response to AIDS and continued with the acceptance of compulsory treatment of recalcitrant TB patients and the endorsement of universal Directly

Observed Therapy (DOT) as the elective strategy in treating TB patients. A related factor in the increased attention to public health can be seen in the alarm caused by the growing phenomenon of drug resistance and by the mounting doubt that too much had been staked on the progress of chemotherapy and drug discovery. Surely the fear and anxious pursuit of security that followed 9/11 was another relevant episode that contributed to this trend.

However, even if we grant that trends encouraging public approbation for QMs exist, we can acknowledge that opposing trends may be at work at the same time, and as the prevailing mood of public opinion changes, the momentum can switch from one trend to the opposite one. For instance, some events that may push public opinion to distrust public health and quarantinism are:

- global failures of public health in handling the Mad Cow Disease in a trustworthy way and the immense cost of the response (see Price-Smith 2009: ch. 5);
- excessive alarm and expenses around swine flu;
- mounting suspicions that fear of terrorism and security anxiety have been exaggerated and have eroded our civil rights and liberties.

The fact that opposing trends may be developing at the same time and vying with each other in their grip over public opinion may seem frustrating and unnerving, but it is an enduring feature of a complex and globalized world in which information circulates rapidly and a plurality of interests and interpretations are constantly interacting.

Understanding these cultural trends is important because they affect the prospects of the success of QMs. Recent positive or negative experiences would affect both the preparedness of PH agencies and the trust and cooperation of the public. Both factors are important in evaluating the chances of successfully enforcing QMs. Although interpretations of events and their impact on public memories and belief are not governed by necessary laws and are open to revision and even to radical changes, they are not completely plastic and they can generate only a limited number of credible narratives capable of orienting people's beliefs and attitudes. So even if we cannot rule out that new events or a changing social climate can

reverse the trend, it is still true that attitudes towards QMs *are different* in 2010 from what they were, say, in 1981 when AIDS was first detected.

I now turn attention to explaining why excessive ambitions about regulating the use of QMs are misguided. To put it simply, the expected benefits and their successful implementation depend on many variables that are not mutually independent. Factors affecting the viability of QMs include: the aetiology and epidemiology of the disease, the geography and demography of the areas affected, the preparedness of health care and public health structures and personnel and their logistic capacities, the feelings of the population affected and threatened and their trust in the health and political authorities, the economic resources of the population and of the government, and the international ramifications of the epidemic. The list could go on, but the important thing to note is that several of these variables influence each other and hence create a high level of complexity and contingency. In a thorough analysis of the lessons learned from the SARS experience, Rothstein and his team propose —among many others—the following recommendations:

The decision whether to order a large-scale quarantine requires a complex analysis of scientific, political, and social considerations.

Public health laws need to be flexible enough to permit appropriate responses to new epidemics and new circumstances (Rothstein et al 2004: 9 and 132).

The last point is supported by the observation that **all six countries that have used quarantines** (during the SARS outbreak) **had to amend their public health laws**. It is revealing that their recommendations are completely focused on what is needed to be prepared to implement successfully large scale quarantines, but they neither venture to say whether quarantines and isolation are efficacious methods of disease control, nor to propose guidelines for deciding when they are worth considering. It is rather striking that a dense 160-

page long report that recommends demanding and costly initiatives as necessary to be able to implement quarantines does not say anything on whether and when they are to be recommended. However strange it may seem, I believe that they are right in not doing so, for such decisions can only be made when an epidemic breaks out and are thoroughly contingent and political decisions, although ones that should be informed by scientific expertise.

However, where these authors are wrong is in calling for a more evidence-based approach to QMs. It may be that a systematic survey of the historical evidence of the effects of quarantines or cordons would produce some interesting suggestions, but in light of the extreme variability and complexity of the circumstances in which such measures were implemented and of the complete lack of any suitable comparable case that can play the role of “control group” we can never expect to achieve any “evidence-based” conclusion about the effectiveness of quarantines. QMs are applied at a societal level, in settings in which it is impossible to control all variables while singling out one to test. Hence no evidence comparable to that afforded by controlled and reproducible laboratory experiments can be expected or hoped for.

In sum, we should not expect the SARS experience to teach us lessons about QMs’s general effectiveness or justifiability. The complexity of circumstances qualifying for the use of QMs prevents the inference of sound general conclusion. We should rather heed the cultural and psychological impact of SARS, for if it is perceived, as it appears, as a success story it may alter both expert and popular attitudes in ways that are going to be relevant in future circumstances.

### **TB in New York City**

*“There has always been tension between the protection of the civil liberties of individuals and the protection of public health. The state has a role to play in both maintaining and protecting freedom and a role in protecting its citizens from threats to their health”*

(Richard Coker).

Tuberculosis (TB) has been a major cause of morbidity and death in the West in the 18<sup>th</sup> and 19<sup>th</sup> centuries. The conditions of crowding promoted by industrialization and urbanization contributed to make it into “the greatest single cause of death and disease in the Western world” (Dubos and Dubos 1987: 110). Nonetheless, throughout the 19<sup>th</sup> and most of the 20<sup>th</sup> century the mortality caused by TB constantly fell, a trend that began well before the disease was recognised as infectious and any cure was found (Sidel, Drucker and Martin 1993, McKeown 1977: ch. 8). But surprisingly in the 1980s this trend was reversed in some western cities and most notably in New York City. By the 1990s the trend turned into an epidemic of TB that peaked in 1992 (3811 new cases) and finally elicited an energetic reaction from the city’s public health authorities.

The response centred on an effort to identify infected individuals, offer them medical care and make sure that they complete their therapeutic treatment. This last target was particularly important, for the city had an extremely low rate of therapy completion (40%), and this failure to bring treatment to completion is a main cause for the development of drug resistant strains of TB. It seems clear that there was as much concern for the growing incidence of TB infections as for the increasing share (19% of cases) of multi-drug resistant tuberculosis (MDR TB). Without the apprehension caused by the latter, it would be hard to understand why there was so much emphasis not only on breaking the chain of contagion, but on making sure that patients completed their cycles of therapy (Coker 2000: 93-111, Bayer and Dupuis 2006: 139). Consequently, the problem arose of how to secure a much higher rate of therapy completion. The problem is that TB treatment is typically long and unpleasant, while the symptoms tend to disappear before treatment is completed. Moreover, a large number of TB patients in NYC have problems of homelessness, alcoholism, poverty, drug-addiction, AIDS and unemployment. The result is that a crumbling public health infrastructure was failing to track and follow difficult patients and assist them in completing their treatment.

The strategy endorsed by the PH authorities in NY was to adopt Directly Observed Therapy (DOT), which consists in not leaving patients to administer the drug on their own, but ensuring this occurs only and always in the presence of health carers. This technique had proved successful in some pilot experiments. In addition, public health authorities claimed that they needed some instrument to discourage dropping out of the programmes and that the only thing that would have been a strong enough disincentive was the threat of detention for people who failed to comply with the prescribed treatment. Although DOT is a new technique, it should be clear that the combination of DOT and detention of noncompliant patients is a “ticket” that fully belongs to the quarantinist family. Unsurprisingly it was highly criticized and contested, but it was nonetheless implemented and delivered quite impressive results, to the point that it has been taken as an example of an effective response to the problem of MDR-TB.

Let us put aside the question of whether or not the initiative of the NYC authorities was justified. What is important for the purpose of this study is that the authorities had to make a difficult decision for which they did not have any unambiguous guidance. Not even the law was clear; they still had considerable public health powers and the precedent of *Jacobson v Massachusetts* on their side, but there was also much more recent jurisprudence that insisted on the rights of patients to refuse treatment, and on the importance of the due process protections. What I want to stress is that whatever decision they would have taken would have been contentious and that their decision could not be grounded on the basis of purely scientific or legal reasons. It was a political decision as well.

Before briefly discussing the political and essentially contested nature of the decision that the PH authorities had to make, there are two other points that need to be stressed. The first is that tuberculosis “is a social and political problem as much as it is a medical problem” (Coker 2000: 189). This is so for two reasons: 1) malnutrition, debilitation, and crowded and poor

housing breed TB, which is mostly a disease of poverty and disproportionately affects the destitute—in fact TB had staggering level of prevalence in the poorest quarters of New York: Harlem and Bronx in particular; and 2) the high percentage of patients living at the margins of society and suffering from homelessness, alcohol or drug dependence and AIDS raised a twin social issue: a) was coercion a form of social control or of discrimination against marginal people? b) Was TB to be blamed on social inequalities and public squalor or on reckless and anti-social individual behaviour?

Another important issue is that commentators agree that a major cause of the NYC epidemic was the breakdown of the public health system at both local and national level.

All these issues are discussed by Richard Coker in a book analysing the TB epidemic in NYC. Coker's arguments are interesting because they illustrate quite effectively the complexity of the political and ethical considerations relevant to the case, and a critical look at his arguments shows how many tensions can emerge among them. Coker is rather critical with the policy adopted in New York and believes that more coercion than was necessary and justifiable has been used and that the rights of the patients have not been respected. Coker also claims that the crisis was the result of a neglect of public health that is the upshot of neoliberal individualism and aversion towards state action. Indeed, he claims that not only is a better endowed public health structure needed, but he goes as far as advocating deep social reforms to create a more egalitarian society in which the conditions that breed tuberculosis are eliminated. This social outlook and broad programme of social and preventive medicine is contrasted with prevailing attitudes in the USA that consist in blaming the victim and denying health services to people who fail to integrate within the accepted way of life. As a result, coercion is not only unnecessary, but a form of social condemnation and indictment of marginal groups.

Coker presents some interesting strategies as alternatives to DOT and argues that since these strategies are less constrictive, they should be given precedence over DOT and detention. I

won't discuss his suggestions on this point. What I find interesting is that Coker first endorses a liberal attitude in opposing any PH intervention that cannot be justified on the basis of the “harm principle”<sup>10</sup>. But later on he strongly criticizes the individualism of American culture and neoliberalism, expressing impatience for excessive limits to governmental action and claiming that positive liberties are not less important than negative liberties. The result is that Coker uses both the liberty of the moderns to reject QMs and the liberty of the ancients as a way of avoiding situations in which the necessity of using QMs emerges. The police powers of public health are excessive from the point of view of individual freedom, but lacking from the point of view of the common good.

This leads us to the next point. Coker criticizes the use of PH as an instrument for expressing moral disapproval and condemnation: this is, he contends, too moralistic a view of PH. But he seems to invest PH with not a lesser moral mission, for he turns it into a spearhead for radical social transformations inspired by ideals of egalitarian justice and solidarity. Neither Coker and other similar advocates of social medicine, nor the people Coker criticizes, stand on neutral moral ground and both views of PH are profoundly political and reflect an enduring ideological rift between conservatives and progressives. The former see in some diseases a sign of individual vice and corruption whereas the latter see in them a sign of a social pathology. In taking their sides conservatives stress individual behaviour as a determinant of health, while progressives emphasize the social determinants of health. No doubt both factors are important and cannot be ruled out on any scientific basis. Let us suppose that we accept the view that the “essential job of public health agencies is to identify

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<sup>10</sup> The principle was famously stated and advocated by John Stuart Mill in *On Liberty*: “That principle is, that the sole end for which mankind are warranted, individually or collectively, in interfering with the liberty of action of any of their number, is self-protection. That the only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others. His own good, either physical or moral, is not a sufficient warrant” (in *Collected Works vol. XVIII*, edited by J.M. Robson, University of Toronto Press, Toronto, 1977, p. 223).

what makes us healthy and what makes us sick, and then to take the steps necessary to make sure that we encounter a maximum of the former and a minimum of the latter” (Gostin, Burris and Lazzarini 1999: 64). The task would not be purely techno-scientific, but would still involve contentious value judgements: how much should we interfere with individual liberties (paternalism seems always lurking), or with the pursuit of other goals (like economic growth or “hedonistic” pleasures) and how many resources are we prepared to spend on preventive measures? A quick reflection here will show that we should not assume that any ideological camp is consistently interventionist or hands-off. Conservatives are more likely to be prepared to be interventionist in matters of drug use and sexual behaviour, while progressives are more interventionist in matters of workplace and transport safety. It seems very difficult to define a mission for public health which is not informed by the ideals or values of some highly contested political tradition or orientation.

My conclusion is that it seems very unlikely that difficult decisions like that faced by the NYC authorities can be decided on the basis of fixed principles and norms for they always touch upon questions that in free and pluralist societies are bound to be disputed and contested. Such decisions need to reflect political decisions and compromises that will vary in time and that need to be open for revisions and for pragmatic testing.

This leads to a further point: the NYC authorities that decided on and implemented the response to the TB epidemic inherited a situation of health emergency and public health disarray that they did not create. Even granting that more enlightened social and health policies in the past would have avoided the crisis, past decisions could not be undone. The price of a failure would have imposed its costs and dire consequences on those very same marginal groups that have borne the greater burden of QMs. The same PH measures that can be seen as punitive for the most marginalised and dis-empowered groups in society, can be seen as necessary to protect the health of these same groups. While violating the liberty of marginalised individuals is open to criticism and suspicion of stigmatization and

discrimination, had NYC PH authorities failed to take action to stop the epidemic, they would have failed to protect marginalised groups from a risk that weighs mostly on them.

In short, a passive stance justified on the basis of respect for liberal individualistic values could have been accused of sacrificing the positive welfare and liberty of the poor in the name of “bourgeois” rights and liberties that they have few opportunities to exercise if they are not granted basic health and social justice.

The above considerations lead to my final point about TB in NYC. The response to the TB epidemic took place in a public health and cultural context that had been deeply influenced by the rethinking of PH strategies stimulated by the AIDS epidemic. QMs had initially been rejected and a new approach based on voluntary prophylaxis and education was developed. Yet, in spite of the role played by AIDS in bringing back TB, it was clear that the different modes of contagion between the two diseases did not warrant the application of the same strategies (Bayer and Dupuis 2006). Commonly the previous epidemic tends to shape attitudes, values, public health capacity and legal precedents, generating a path dependence that may prove challenging to overcome, and inhibit the ability to give due consideration to the specific features and challenges of the new epidemic (Baldwin 2005: Introduction and ch. 3). The only antidote to the risk of having PH officials “fighting the previous war” is to allow them flexible public health powers rather than straight jacketing them with too many constraints.

### **The first decade of the AIDS epidemic in the USA**

*“The protection and promotion of the health and welfare of its citizens is considered to be one of the most important functions of the modern state”*

(George Rosen)

The first alarm about what was to become the HIV/AIDS epidemic was sounded in June 1981 by the Centre for Disease Control and Prevention (CDC). By 1982 a clinical definition of AIDS has been developed and the mechanism of transmission understood. In 1983 the retrovirus responsible for the disease was isolated and by 1985 a test to detect antibodies became available. At that stage though, AIDS was unfortunately a worldwide emergency. This new disease is quite peculiar. It has a very long latency period during which it causes only inconspicuous minor symptoms, but eventually it overcomes the immune defences of the patient and while not killing him/her directly, opens the door for opportunistic infections that kill the patient. Among the early most common opportunistic killers were some very uncommon infections like *pneumocystis carinii* and even a cancer (kaposi's sarcoma). The beginning of the epidemic was thus characterized by scientific bafflement and media sensationalism, for the disease was soon associated with homosexuality, promiscuity, prostitution and drug injection.

Journalists vied with each other for the most lurid stories and AIDS rapidly became 'the gay plague', fuelling prejudices and causing panic. Not since syphilis was rife has such a sense of fear and guilt been engendered by an infectious disease (Crawford 2000: 56-7).

Scientists were more sober, but no less baffled. As Robert Gallo (who contributed to the isolation of the virus) noted:

The consensus was that retroviruses did not infect humans, that viruses did not cause cancer and that infectious diseases were a problem for the third world but not for us (quoted in Zuger 2003).

The public health response too proved to be sober and remarkable. To understand it some background facts are needed. Let us begin with biomedical and epidemiological facts. The first key factor is the route of infection. AIDS is communicated through contact between bodily fluids: semen, vaginal secretion and blood and as such is not easily communicable and

allows people to take precautions to avoid infection. It is amenable to behavioural control.

From the epidemiological perspective, in the USA (and henceforth I refer to this country unless otherwise stated) the epidemic initially affected almost exclusively 4 specific groups: homosexual men, intravenous drug users, Haitians, haemophiliacs. Of these gay men were by far the most affected group.

Next we must consider the cultural background. Since the 1950s the country had experienced a constant stream of struggles and campaigns to affirm and extend civil rights and to stop discrimination<sup>11</sup>. The black community, feminists, gays and lesbians were all protagonists of transformative social movements. The campaigns to change social attitudes towards mental illness and disability are perhaps less celebrated in the popular imagination, but equally important for our present subjects. The so-called anti-psychiatric turn promoted a less paternalistic, less authoritarian and more tolerant and humane treatment of people with mental illnesses. The most remarkable effects were a massive deinstitutionalization of patients and the recognition of their right to refuse treatment. Meanwhile a series of Acts were passed giving unprecedented protection to the rights of non-discrimination and equal opportunities for disabled people<sup>12</sup>.

Of great importance are also the changes that took place in the sphere of sexuality and intimacy. From the Kinsey report to the contraceptive pill to the experiments in free love, it was a *crescendo* that changed intimate relations and transformed sexuality into a sphere of

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<sup>11</sup> The *Civil Rights Act* of 1964 and the *Equal Employment Opportunity Act* of 1972 did much to outlaw discriminatory practices based on religion, nationality, ethnicity or gender.

<sup>12</sup> The *Rehabilitation Act* of 1973 established the principle of non-discrimination on the basis of physical disabilities. Later the *Civil Rights Restoration Act* (passed in 1988) extended such guarantees to seropositive citizens. This movement towards the protection of victims of impairments and disadvantages was completed in 1990 when the Americans with Disabilities Act was passed (an act whose relevance for the application of liberty and rights restrictive measures to HIV patients was soon acknowledged) (cf. Baldwin 2005: 102-106).

free individual choice, self-expression and self-discovery: in brief a stronghold of individual autonomy and privacy.

Public health too had undergone some important transformations. The introduction of antibiotics, the decline of infectious diseases and the epidemiological transition had transformed the agenda and the concerns of PH. QMs were rarely used and never on a mass scale, while the attention was instead being redirected towards the prevention of chronic diseases and accidents. These included great efforts to promote behavioural changes, most clearly exemplified by the campaigns against tobacco and to promote road safety (helmets, safety belts).

Finally, anti-governmental feelings and suspicion towards the public administration and its bureaucracies—though by no means new in the history of the country—reached an unprecedented height, to the point of finding expression in president's Reagan inaugural speech: "In this present crisis, government is not the solution to our problem; government is the problem"(Reagan 1981).

Though regrettably stylized and simplistic, this background is enough to demonstrate the broad variety of factors that shaped the response to the epidemic. However, let us not forget that public health is largely a responsibility of individual states and local administrations and therefore broad variations occurred. It is important to note that the epidemic was unevenly spread, with 4 states (California, New York, New Jersey and Texas) accounting for the great extent of the epidemic and two cities —San Francisco and New York— setting influential examples. With these qualifications in place, let us examine a very significant example of the official response to AIDS provided by the General Report on AIDS issued in 1987 by the Surgeon General and addressed to all American citizens. The report insisted that AIDS was not easily communicated and could be stopped and prevented if the whole population took responsibility for adopting the necessary prophylactic measures and avoiding risky behaviour. The emphasis was therefore on voluntary behavioural change, on education and on an equal sharing of responsibilities between infected and non-infected citizens. Infection

required intentional actions both from the carrier and from the receiver of the infection, and it was within the latter's power to take precautions and avoid contagion. The Surgeon General explicitly addressed the problem as concerning every single American citizen and not only those infected. He firmly rejected the idea that quarantine, isolation and compulsory screening offered sensible solutions. Similarly stigmatising AIDS patients could not be a solution and the Report ended with an unambiguous rejection of discrimination:

AIDS should not be used as an excuse to discriminate against any group or individual (Surgeon General 1987).

Generally speaking the response strategy was centred on education and the attempt to win voluntary cooperation and self-restraint from infectious citizens. Care was taken not to feed on patients' fear of stigmatisation, coercion or legal prosecution. Protecting their privacy and anonymity was considered paramount in order not to alienate them from health institutions and "drive them underground".

However, QMs did not disappear entirely. All immigrants were tested and refused entrance if found HIV-positive; 2,5 million aliens were tested before being granted legal residence; AIDS was a reportable disease in all states; confidentiality was far from absolute and notification to partners was allowed when their health was at risk; in several states isolation orders could be issued (and in some were issued) for patients who failed to refrain from dangerous behaviour; mandatory testing was carried out within the army and the foreign service (Baldwin 2005, Bayer and Fairchild-Carrino 1993, Bayer and Kirp 1992b).

Nevertheless the prevailing official strategy appeared to be a significant departure from traditional PH policies and the profile of a new approach (or even paradigm) emerged : it was centred around universal education, behavioural change, respect for patients' rights (above all privacy, informed consent and confidentiality), involvement of patients as a result of their assertive and successful activism and mobilisation. This approach came to be seen as a new

fashion of PH variously labelled as “liberal”, “voluntarist”, “cooperative-and-inclusive” (Harrison 2004, Baldwin 2005, Bayer and Kirp 1992a).

However, the concept that has proved more successful and controversial is that of an “AIDS exceptionalism” first proposed by Ronald Bayer (Bayer 1991). The “exceptionalist” thesis has a descriptive and an evaluative interpretation, the first of which asserts that the AIDS epidemic has been treated differently from previous ones, while the second claims that AIDS ought to be treated differently. Both interpretations are contentious. From a descriptive point of view exceptionalism relies on a comparison with conventional PH approaches to IDs as they emerged in the 19<sup>th</sup> century and based on coercive quarantinist techniques. Against such a benchmark, the response to AIDS described above displays some remarkable differences. Yet Scott Burris has criticized the descriptive accuracy of the exceptionalist thesis (Burris 1993-4). His attack is based on two different claims: 1) concern for the protection of the victims has by no means been general and consistent: legislative responses and local authorities’ initiatives have varied considerably and in many cases repressive, traditional and discriminatory initiatives have not been stopped. This, he claims, also demonstrates that civil rights and gay groups are far from being as powerful as it is generally assumed. 2) From a historical point of view, he argues, AIDS is well within the track of what happened with previous epidemics, in which politics has always been very present and controversies have raged. This shows that the hypothetical “traditional public health approach” never existed, for policies and responses have always been the results of disagreements, conflicting interests, practical possibilities and negotiations.

Burris makes important points that need to be acknowledged, but exceptionalists can still point to some genuine novelties like the unprecedented vocal activism of patient groups, concern about stigmatization and discrimination, and the insistence on civil or human rights. Similarly, while gay activists were not all-powerful, they surely did strike remarkable successes, most notably the revision protocols on new drug testing and distribution (Danziger 2000). On balance, it seems that both sides have sound arguments while pushing some claims

too far. However one point made by Burris is strongly backed by public health history: responses to epidemics present a staggering variety that seems to derive from the high variability and contingency of the facts determining the response: biological, clinical, epidemiological, geographic, cultural, religious, political, legal and pragmatic—including logistic and economics (Baldwin 1999).

Before turning to the evaluative interpretations of exceptionalism, let us briefly see why it came to be seen as a passing feature of the response to AIDS. The core of exceptionalism resides in the resistance to the “gentler” set of QMs: testing, reporting and notification.

Against such measures, that were standard for STDs and not without a clinical rationale, were pitched the fears of discrimination and the right to privacy. But it was precisely around these measures that the consent broke apart from the late 1980s. Advances in therapeutic intervention made the case for all measures likely to increase early detection much more compelling and the medical and public health personnel gradually dropped their support of exceptionalism. Clinical advances were crucial but epidemiological changes were also relevant. AIDS moved from being largely a gay disease and took the more familiar profile of affecting mostly the poor and marginal ethnic minorities. This contributed to making patients’ voices far less audible. Not even what looked like the ethical core of exceptionalism was safe from contingencies.

Evaluative appraisals of exceptionalism are diverse and it is interesting to see how ideological orientations affect them and views of QMs. Supporters of exceptionalism see it as an ethical advance and the herald of a new era in public health in which human rights are central and patients are given voice and power (Mann 1996-7). Critics of exceptionalism see it as motivated by an individualistic and bourgeois ideology unable or unwilling to see that liberal rights are mere rhetoric for the powerless and dispossessed who live in contexts of “structural violence” and oppression (Danziger 2000, Scheper-Hughes 1994, Farmer 2001, ch. 3). In those contexts, QMs may well defend the vulnerable better than individual rights—as Cuba’s case shows (Scheper-Hughes 1994, Farmer 2003, ch. 2). More moderate

views emphasize the contingent nature of the circumstances that have produced exceptionalism and are willing to admit that it presented lights and shades—the involvement of patients is a welcome inheritance to be preserved, while some resistances to testing, notification and reporting are judged as ideologically biased and untenable (Bayer 1991, Bayer and Kirp. 1992c, De Cock & Johnson 1998). Some see exceptionalism as motivated by a desire for reparation from past injustices, but in the end unjust because it creates new forms of injustices and privilege (Casarett and Lantos 1998: 756-9). Finally Burris rejects the “standard” picture of exceptionalism’s drawbacks as misleading and motivated by a conservative agenda eager to restore quarantinism and unjustified coercion; but he advances an alternative view of which innovations seen in the AIDS response are worth defending: a) the new tradition of PH developed in the fight against chronic diseases, b) a new commitment in the Supreme Court jurisprudence to protect citizens from restrictive or coercive measures based on popular prejudices and demanding scientific evidence to justify restrictions of rights and liberties.

What the AIDS experience shows is that responses to epidemics are dependent on a huge variety of factors and that these are both changing and open to conflicting interpretations and evaluations. Furthermore, it shows very clearly the dynamic nature of an epidemic as an evolving entity (some would say construct). Even around a disease like AIDS in which more factual considerations—biological, clinical, epidemiological and logistico-economic—go a long way in making the case for or against any QM, ethical and ideological disputes over fundamental political themes are rife and unavoidable. Finally, AIDS illustrates the force of both scientific and political factors: the reality and force of both facts and interpretations.

## Conclusions

*“A commonwealth is the weal of the people;  
but a people is not any and every sort of human association  
brought together in any fashion whatever,  
but an association of many united in partnership  
by consent to law and by sharing of interests”*

(Cicero)

Allow me briefly to recapitulate the main point that I have argued thus far. First I have shown that emerging and resurgent IDs are an enduring risk for developed countries too.

Furthermore, their return is caused by social, economic and ecological conditions that are unlikely to change in the near future. As a consequence QMs are not likely to disappear from the “toolkit” of PH: they still have a contribution to offer in a variety of not unlikely circumstances. Finally I have argued that notwithstanding their usefulness in certain circumstances, QMs are bound to be controversial, because both arguments for and against their use are supported by good reasons and are steeped in values entrenched in our political traditions.

The case studies have highlighted the great array of variables relevant in making decisions about the use of QMs. Uncertainty and contingencies are pervasive, thus decisions need to be sensitive to particular circumstances and rely on good judgement. Norms, regulations and prescriptions can barely cope with the complexity of the circumstances of choice. In fact, the case studies have also shown that a need to break away from previous practices and to amend existing norms may lead to changing statutes or long-term strategies. Moreover, our case studies have shown the impossibility of disentangling politics from biomedical sciences, and facts from values. Finally, we have seen that, far from being static, every epidemic is a fluid and dynamic phenomenon, calling for flexibility, ongoing monitoring and revision of policies.

It has been said that “public health ... has as its chief duty the unenviable task of providing common goods and controlling negative externalities” (Gostin, Burris & Lazzarini 1999: 68). This can be interpreted to mean that PH has two different but equally important tasks. It has a positive duty to pursue the goal of promoting population health, a duty pursued through a constant and relentless labour of surveillance, education and prevention. This is the ordinary business of PH, based on mid- and long-term projects and raising potentially radical demands of social reform. We may call it the “chronic” dimension of PH. Additionally, there is the duty of tackling health emergencies like severe epidemics. This is pursued through extraordinary, *ad hoc* and short-term interventions. We may call this the “acute” dimension of public health.

I argue that these two dimensions of PH should have a greater degree of independence as they respond to different requirements and different forms of accountability. Yet they have one thing in common, they need to acknowledge the role of the human will in shaping their policies so that the present emphasis on regulation and the law be counterbalanced by making room for the appropriate expressions of human decisions. Crucially, the kinds of will involved in each dimension are different and need different institutional mechanisms to be deployed and controlled. In “acute” PH we need flexibility, quick but responsive decision chains, and latitude in the use of power. In “chronic” PH what is needed instead are mechanisms of political legitimation and institutional settings that encourage the democratic formation of a political will. Chronic PH—because of its deep social and moral implications—needs political justification, while acute PH needs eminently a technoscientific justification—because success is here all-important and coincides with the public good. In both cases in order to make room for the technocratic and the democratic will, ethical and legal norms need to take a step back—and of course that does not mean eliminating them, but preventing them from suppressing or suffocating the moment of decision.

In the following section I sketch a proposal for PH emergencies, which is meant to be a stimulus for further discussion. This proposal is then followed by a theoretical discussion of the reasons why PH cannot be politically and ideologically neutral. This is a call for more attention to the socio-political dimensions of PH, which need more theoretical work and more public discussion.

*Extraordinary powers and ex-post accountability for reasonableness*

*“Il faut cesser de toujours décrire les effets du pouvoir*

*en termes négatifs: il «exclut», il «réprime» [...]*

*En fait le pouvoir produit; il produit du réel”*

(Michel Foucault)

I have argued that emergency situations in which QMs may be useful are characterized by uniqueness, contingencies and fluidity. I have also suggested that this requires an *ad hoc* response and that laws, regulations and fixed protocols are likely to be often unhelpful or even counterproductive. This may suggest a radically different approach to PH emergencies, based on *ad hoc* and strictly temporary crisis units with a definite mission and extraordinary powers. This would have several advantages:

- maximal responsiveness to the uniqueness and contingency of the crisis;
- flexibility;
- quick and efficient chain of command and decision;
- concentrated power;
- minimal vested interests;
- minimal interference with the ordinary PH structure;
- no “leftovers” (i.e. no emergency laws, no permanent agencies left behind).

These features do have their downsides and inconveniences, but on the whole I believe that a special commissioner charged with establishing a temporary, high profile task force, and entitled to override laws and regulations would have an epistemic and efficiency edge on any existing structure. This claim about effectiveness is of course open to challenge, but rather than defend it I am going to focus on the aspect that is surely going to cause outrage and criticism. You may ask, how can we give to anyone the power to override existing laws and rights?

This is no small risk, but I offer two reasons for reassurance: 1) it can be checked; 2) there is a trade off between biological risk and political risk—or in McNeill's terms, between the risks of microparasitism and macroparasitism. If the political risk can be kept under check, the bet may not be a bad one. Consider the following outline of an emergency task force:

1. The emergency commissioner is appointed by the executive power in response to a request by the branch of PH devoted to surveillance.
2. The commissioner and task force are strictly temporary and not renewable.
3. The commissioner's conduct is constantly scrutinized by two specially appointed committees: a technical one appointed by the ordinary PH authorities and a political one appointed by the parliament. The committees act as a watchdog: they can advise but not interfere or veto.
4. The commissioner has a strict obligation of unrestricted publicity, transparency and truthfulness in reporting to the committees and to the public.
5. The commissioner can override laws and rights, but has to present a justification to the committees.
6. If both committees express distrust in the operation of the commissioner, and an appropriate defence does not restore the trust, the appointment is revoked.

7. The commissioner can issue temporary orders but not laws, hire personnel and experts, but cannot make any lasting appointment; can override—but not abolish—laws and rights.
8. At the end of the mandate, the commissioner’s conduct will be assessed by a committee of experts appointed in part by the parliament and in part by representatives of the medical and scientific community.

This model of accountability is based on openness, transparency and on a final *a posteriori* evaluation of overall achievements and of the means adopted. It is to be contrasted to models based on set procedures, formal targets and requirements. An evaluation of this kind seems adequate to achieve the twin goal of preventing power abuses while encouraging the leadership and latitude needed in facing unknown challenges.

*Normal times and radical reforms: Public Health’s quest for legitimacy*

“After all, every legal order is based on a decision,  
and also the concept of the legal order ... contains within it  
the contrast of the two distinct elements of the juristic  
—norm and decision”

(Carl Schmitt)

The western political tradition is permeated by the opposition between two sources of legitimacy: the Law and the Will. Political thought has oscillated between the opposing views that *Lex facit regem* and that *Rex facit legem*. Greek democratic *poleis* gave precedence to popular will, Rome found a remarkable balance, while medieval institutions put the law above will. The formation of modern states under absolute monarchies was led by the hegemony of will, as were the French revolution and its offspring: nationalism. Liberalism by contrast slowly tamed the modern state and brought it under the dominion of the constitution. In our current liberal-democratic tradition liberalism represents the side of the law

(constitutionalism) and democracy the side of the will (popular sovereignty). This opposition largely mirrors the one between modern and ancient liberties discussed earlier.

The practical relevance of the theoretical tension between law and will becomes clear as soon as we see its effects on the conceptions of a) **the powers of the state**, and b) **the functions of the state**—and of course of their limits. Political ideologies have distinctly different views of the relative balance between powers and functions. Classical liberalism—concerned with individual (modern) liberties—wants to keep both to a minimum, while ideologies with a strong view of the common good (e.g. socialists, nationalists, communitarians) are willing to expand both. There are also mixed positions; egalitarian liberals try to expand functions while limiting powers, while conservatives do it the other way round. This is by no means an abstract question of taxonomies, but has great consequences to public health.

We can distinguish two main traditions in public health. The most ambitious tradition (exemplified by figures like Rudolf Virchow and Geoffrey Rose) takes very seriously the imperative of promoting health (Oppenheimer, Bayer & Colgrove 2002; see also Baldwin 2005: 11-9; and Baldwin 1999: 10-5 and 536-49 for a more complex view of the relation between political orientations and public health measures). It is thus prepared to urge for radical social reforms in order to improve population health. This requires extensive state powers and broad scope for state functions. Unsurprisingly such views have been put forward by socialists or radical democrats. The other tradition is classic quarantinism, inspired by the contain-and-control strategy. It is much less ambitious and more hands off in normal times, but claims strong powers when health and safety are threatened by a crisis. Unsurprisingly this looks more conservative and is more inclined to expand state powers than state functions. In spite of their important differences both traditions of public health reject the minimalism of classic liberalism. They are both prepared to give more weight to the common good and to the popular will (liberty of the ancients) than classic liberalism. Public health therefore cannot help relying on political will and hence needs some form of legitimation through democratic will.

We have already encountered a third option for public health in my discussion of Coker. He wants to expand the mission of public health to reduce social inequalities (he advocates broad functions for the state), but criticizes an easy use of QMs because he resents state encroachments on individual freedom. In short, he wants to expand functions and limit powers. This is the liberal-egalitarian position, which finds its main expression in the attempt to bring together human rights and public health. Attractive as it may be this position looks to me theoretically unstable and unable to stand the test of realism.

The problem of insisting on individual human rights in public health is that it produces a sort of Janus-like approach in that it is too dependent on the temporal perspective that is adopted. If individual rights are emphasized during a health crisis they are likely to oppose any strong and radical initiative threatening substantive or procedural rights. If instead the perspective of individual rights is adopted when no health emergency or alarm is operating, then it seems to stress the positive rights to health and well-being and to require very active and interventionist policies in promoting health. Now the problem is that in doing so the emphasis on rights runs the risk of being a double failure for lack of realism. In times of emergency, fear and panic will likely override concerns for rights, while in quiet times economic interests, social inertia and vexed interests—backed by individual property rights—will prevent ambitious reforms from gaining support and being implemented. The irony is therefore that the emphasis on individual rights may turn out to be conservative and timid in times of action—thus failing to protect the most vulnerable segments of society—while being visionary but too utopian in times of social complacency and inaction—thus letting the more vulnerable down again.

In these final proposals and reflections I have tried to give expression to what I believe is the warning offered by an analysis of the case studies informed by political theory: it is better to have emergencies tackled by experts and reforms informed and legitimized by democratic debate, than to have reforms decided by technocrats and responses to emergencies hampered by ethical and political disputes.

