Health systems need health democracy

Françoise Barré-Sinoussi, Paul Benkimoun, Olivier Nay and Stéphanie Tchiombiano
signed this opinion page, on behalf of the think tank Santé mondiale 2030.
It was published in the French Daily newspaper Libération*, March 4, 2022 : "Health, with patients, not without them"*
The translation was done by Olivier Nay.

On March 4, 2002, France adopted the so-called Kouchner law, which constitutes the legal basis of the concept of "health democracy", to which the law devoted 41 articles. This concept goes far beyond the French case by enshrining in law the importance of patient and citizen participation in health policies. This law was drafted with the support of associations of users of the health care system and the participation of the population in the "états généraux de la santé", a large consultation organized in 80 cities in France. Inspired by the HIV-AIDS movement, it aimed to target the most vulnerable and to protect patients' rights (such as the rights to consent, to data confidentiality, to medical records). But it was also and above all a recognition of collective rights intended to increase the participation of all users in the development and implementation of health policies. This law was driven by political philosophical consideration on health as a "primary good", to quote John Rawls, which means a good to which all individuals should have access regardless of their status and position in society.

20 years later, has the law been enforced with success? Almost everywhere in the world, the response to Covid-19 has been characterized by a significant return to vertical health strategies and a distrust to social bodies. Any comparisons with the mobilization of associative actors in the fight against AIDS in the 1980s would be misleading: the two diseases are very different (chronicity and high lethality of AIDS at the time, affecting a community already united against homophobia). It is logical that the Covid crisis has not led to the same community mobilization. Certainly, the fight against a long pandemic, marked by several waves with multiple impacts, required strong coordination of government services and centralized decision-making. The approach of decision-makers would undoubtedly have been very different if governments had anticipated the duration of the crisis. However, beyond the need to inform the public, we have seen, all over the world[1], how little citizens have been consulted, how little they have been involved in the consultation or decision-making processes.
The claims for participation are numerous. In the spring of 2020, the president of the French Scientific council Covid-19, the French Society of Public Health and France Assos Santé (which brings together 83 associations of users of the health system) asked the Prime Minister to create a liaison committee with civil society. Their demands have never been met. Interesting initiatives have been put in place, particularly in large French cities. But how can we explain the fact that, overall, citizens have been so little involved in decision-making?

[1] For an equitable COVID-19 response, investments in civil society cannot wait, UHC 2030, 21 September 2020.

It must be admitted that the vast majority of political and administrative elites worldwide continue to distrust the public. They still believe that ordinary citizens are not educated, insufficiently rational, and lack the political skills to get involved in decisions. Citizens have thus, in a way, been considered as obstacles to the good governance for urgent and complex situations. This political elites do not take into account the profound societal changes and the growing demand for each individual to be part of his or her own health monitoring, to be informed and to be involved in decision-making. This lack of consideration has fueled mutual distrust. It has been conducive to the propagation of false news and has reinforced the risks of consolidation of a counter-society open to conspiracy theories. Combined with restrictive measures for daily life, it has also led individuals to a perception of loss of control over their lives, a loss of meaning, and a deterioration of mental health, as we observe especially among young people.

Citizens' inclusion and participation in public health governance is not only an ethical issue[2], but also a policy question[3]. This dimension is often neglected by executive powers. Inclusion and participation are both guarantees of the adaptation of measures to the experiences of citizens, and important conditions for policy adherence. They also make it possible to legitimize decisions taken in the name of the common good and to ensure trust in political authorities, which conditions long-term health policy, as well as for crisis management. Citizens' trust in health institutions is built up over time; conversely, it can collapse rapidly.

Researchers specialized on risk communication have long understood these aspects. Although some institutions have followed them, they do not yet seem to be heard by policymakers. As mentioned by the US Environmental Protection Agency, "risk communication is a two-way exchange, in which institutions inform target audiences of possible risks and, in turn, gather information from those exposed to those risks" [4].

As with all global threats, such as climate change, the response to upcoming health challenges cannot overlook the participation of social communities and citizens. It will give them a voice, strengthen participation bodies and promote the inclusion of vulnerable or marginalized populations. It will involve international, national and local policy coordination[5]. For effective and fair responses to health challenges, societies will have to combine the knowledge of patients and family caregivers with the scientific and clinical knowledge of health professionals.

Both the Kouchner law and the lessons learned from the Covid-19 management show that social participation is an essential component for quality and efficient health systems. In France, as in other countries, "health democracy" is still absent from discussions on health reform. Not only should everyone have equitable access to the

---

[2] L'inclusion et la participation de toute la société à la réponse au Covid-19. Éléments de réflexion. Santé mondiale 2030, Avril 2020. http://santemondiale2030.fr/wp-content/uploads/2020/04/Note-inclusion-société-face-au-Covid-19-1.pdf

[3] Bovens M (2007), « Analysing and assessing accountability: A conceptual framework », European Law Journal, 13 ; 450.

[4] USEPA, United States Environmental Protection Agency, "Considerations in risk communication: A digest of risk communication as a risk management tool," Washington, DC. 2002.

[5] Abelson, J., Blacksher, E. A., Li, K. K., Boesveld, S. E., & Goold, S. D. (2013). « Public deliberation in health policy and bioethics: mapping an emerging, interdisciplinary field ». Journal of Public Deliberation, 9(1).

health system, but all those who wish to do so should be able to take part in the decisions that are made in the name of the common good.