



Paris, France

barbara.casassus@gmail.com

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## PATIENT CENTRED CARE

# Covid-19: French sidelining of patient associations is a global trend

French patient associations are angry that politicians have called on scientists but ignored civil society in devising strategy for the pandemic. But France is not the only country guilty of this, writes **Barbara Casassus**

Barbara Casassus *freelance journalist*

Health democracy in France vanished on day one of the pandemic, says the president of France's patient associations. "We are shocked that we were not invited to join either of the two official experts committees set up to help handle the crisis and were not consulted on the conditions for imposing or lifting the lockdown," says Gérard Raymond of France Assos Santé, which represents 85 of the country's patient associations.

By law, all hospitals and clinics must have a patient committee. So too should governing bodies, a requirement bolstered by a new law in 2002. Representatives from France Assos Santé are now on the governing board of half a dozen national health agencies and scores of regional ones. These include the National Agency for the Safety of Medicines, the French National Authority for Health, and the health ministry's advisory body, the Health National Conference.

"As soon as the crisis began, we offered our services to improve communications and overcome the public's mistrust of government decisions, but we had no reply," Raymond says. He followed up on 11 September with an open letter to the prime minister, Jean Castex,<sup>1</sup> again calling for the government to include patient representatives and advocating a series of proposals to reverse the resurgence of covid-19. As of 22 October, he had still received no reply. *The BMJ* has also contacted the ministry for comment.

Jean-François Delfraissy, who chairs the covid-19 scientific committee that advises the government, tried to help. According to French news outlet *Mediapart*, he sent a confidential message to President Emmanuel Macron, former prime minister Edouard Philippe, and health minister Olivier Véran on 14 April, urging them to involve civil society in managing the health crisis.<sup>2</sup> The letter says that this would avoid stoking criticism of "authoritarian management and being disconnected from people's lives."

Delfraissy urged Philippe to create a citizen committee that would form a liaison between the general public and the authorities in the medium or long term. But Philippe said "it was not a priority," as the government was already in discussions with non-governmental organisations. Delfraissy told the annual meeting of the European Health Forum Gastein on health democracy in action on 2 October: "I don't understand" and "believe it was a great

mistake." He was particularly surprised in light of citizen involvement in the latest French bioethics law in 2018.

## Global trend

The exclusion of patient groups from official crisis management policy is mirrored across the globe, says Kawaldeep Sehmi, chief executive officer of the International Association of Patients' Organizations (IAPO).

If policy makers in other countries had sought IAPO's advice about shielding programmes, the measures would have been much less severe for the general public, claims Sehmi. "We would have advocated test, trace, and treat and isolating high risk people from the start," he says. "If the authorities had contacted their country's rare diseases association, it would have put out the word immediately, and I am 100% sure that the public would have signed up to it."

Most governments and health authorities have dismissed patient associations' calls for emergency measures to protect people with chronic health conditions by allowing and facilitating treatment for non-covid cases. The problem is particularly acute in countries with no or weak social welfare systems, says Sehmi. "Like in wartime, some patients feel guilty for seeking non-urgent medical care, as they see it as drawing resources away from the front line."

IAPO has repeatedly asked the World Health Organization to urge member countries to involve patient associations in this pandemic and maintain the policy for the future. *The BMJ* contacted WHO for comment but has yet to receive a response.

In Europe, feedback on patient organisations' lack of involvement is anecdotal for the moment, says Katie Gallagher, senior policy adviser to the European Patients' Forum (EPF) in Brussels. The organisation, which represents 74 public health and health advocacy groups across Europe, is conducting a survey of the impact of covid-19 on patients and patient organisations. The results should be released towards the end of November.

A *BMJ* editorial published on 1 July emphasised the importance of patient involvement in crisis planning.<sup>3</sup> In response, the EPF said in a statement: "While the value of patient centredness is recognised in theory, and increasingly at political level, the patient community was disappointed to witness the almost complete sidelining of even statutory commitments

to patient and public involvement during the acute phase of the covid-19 crisis.

“The crisis proved that despite rhetoric, patient centredness is not yet truly embedded in healthcare and is still regarded as ‘nice to have’ rather than one of the essential elements of healthcare quality.”<sup>4</sup>

## Exceptions

There are a few exceptions to this global trend. South Korea and Taiwan have involved patient groups having learnt lessons from the SARS and MERS outbreaks in 2002-03 and 2015, respectively. “In Korea, after MERS, a consensus has been formed between patient, consumer, and civic groups based on trust in the government and quarantine experts,” Gi-jong An, president of the Korea Alliance of Patients’ Organizations, told *The BMJ* in an email. “This trust is one of the factors for which [covid-19 prevention] is successfully evaluated.”

Another exception is England. “We have been involved in designing strategy in England to some extent,” says John Kell, head of policy at The Patients Association, “The Department of Health and Social Care and the NHS have sought our opinion on a number of issues, such as the wording for an NHS letter encouraging patients to resume treatment for long term conditions.”

Back in France, small steps are being taken. In March, Olivier Véran and Nicolas Revel, former chief of the national health insurance fund, did seem to take notice when Raymond warned of the risk to employees returning to work after lockdown. As a result, people with one or more in a series of conditions such as obesity, diabetes, or cardiovascular problems have been permitted to take sick leave on full salary since 25 April. Raymond is now hoping to persuade the government to extend the list of qualifying conditions. His calls to ensure that patients with chronic diseases continue their treatment and are able to consult their doctors remotely also seem to have been heeded.

The major moves, though, seem to be at regional rather than national level. Municipal governments plan to set up citizen committees in Paris and about 14 other major cities. Delfraissy told *The BMJ* that he hopes some if not all will be in place by the end of November. “This is a good solution [and is] better late than never.”

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