

Long Covid : Open letter

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Long Covid : an open letter signed by more than 200 scientists, health workers, citizens and member of organizations, from 12 countries

"The data is clear : Long COVID is devastating people's lives and livelihoods".

These are the words of Dr Tedros Adhanom Ghebreyesus, Director General of the World Health Organization (WHO), who exhorts world leaders to seriously intensify their actions to tackle Long COVID.

This strong, resolute speech is all the more striking in comparison to the stagance and silence regarding this illness in France, despite it affecting more than 2 million adults, according to *Santé Publique France's* estimates (shockingly, *Santé Publique France* completely excluded children from their survey). This silence, which includes that of the French Health Minister and French health authorities, was followed by COVARS' first opinion as the new French Scientific Committee on Health Risk Monitoring and Anticipation.

COVARS fails to take Long COVID into account as a motivating preventive factor of Covid infection, despite its being a possibility even among those with a mild form of Covid. This stance was foreshadowed during one of the COVARS committee chair's radio interviews, in which Covid was described as a "severe cold, [that was] not too serious" for the vaccinated population. In doing so, the very existence of a chronic illness as well as the long-term sequelae due to Covid-19 were buried.

When COVARS does refer to "persistent forms of Covid-19" in its opinion, it does so 1) within the context of a nonexistent, scientific debate as to the imputability of symptoms "regarding SARS-CoV-2 or another triggering factor" and 2) to qualify them as "psychosomatic", "poorly understood", and "little-studied", contrary to both the recommendations of the HAS (French Health Authority) and existing scientific data.

Notwithstanding, over 2000 international science publications have appeared in two years. The scale of research on Long COVID is unprecedented and due to the considerable funding allocated by other countries: \$1.15 billion in the US since 2021 (without taking into account private funding) and £50 million in the UK. A mere €9.5 million has been allocated in France, a budget which, to date, is not set to increase in 2023 despite the WHO's entreaties to increase resources for Long COVID.

Though the precise pathophysiological causes of Long COVID are yet to be fully elucidated, there is an established consensus on certain elements. The neurological, immunological, cardiovascular and renal sequelae (among others) are a well-established reality that is not, contrary to what COVARS has claimed, the object of controversy among scientists. The theory of a non-physiological ("psychosomatic") origin - a theory proposed by a French team of researchers, is the only causative theory cited by the committee. It is, in reality, a marginal theory with no presence in any notable scientific reviews. This incomprehensible stance by COVARS, whose mission is to advise governmental decision makers, is prejudicial, and places the quality of life of millions of people at risk - both in the short and long-term. Patients are already suffering the consequences of the "psychosomatic" theory of Long COVID, reinforced by the committee's opinion, as they have been prevented from receiving safe, suitable treatment protocols. This places Long COVID patients' health at risk, most notably those experiencing post-exertional malaise. The few medical centers treating Long Covid are often overwhelmed and staffed by overworked and exhausted medical personnel who lack resources. No pediatric Long Covid clinic has been created in France, despite its presence in numerous other countries (Switzerland, Spain, Germany, the UK, etc.).

Thus, each day in France, for 2+ years for some, children and adults ill with Long COVID struggle, not only with a multitude of symptoms (over 200 have been reported) which heavily impact the quality of their professional, scholastic, and social lives, but also with the difficulty in receiving proper diagnoses and decent medical treatment, as well as a lack of structural and financial support. From March 2020 to February 2022, less than 4000 patient applications for long term illness recognition (ALD) were accepted in France. Overwhelmed and exhausted, ashamed of an invisible chronic illness, many patients wander to and from medical practices - or forgo care altogether - resulting in the severe individual and societal socio-economic impacts reported in the financial press.

No significant progress has been made since the announcement of the French Long COVID action plan by Olivier Veran and Xavier Lescure, in March 2022. Also, despite the unanimous approval of law n. 2022-53 in January 2022, regarding the creation of a platform to register and treat those who became chronically ill due to a Covid infection, this law has yet to be implemented.

We are dismayed as France persists in its inaction and denial of the reality of Long COVID. Whether the result of ideological posturing or as the consequence of a rhetoric artificially signaling the end of the pandemic, the reality of Long Covid has been deformed: COVID-19 is not a "severe cold". While vaccination and therapeutics offer a measure of protection against acute disease and death, 32,000 people have died since the start of January 2022 in France - and the vaccine's protection against Long COVID is estimated to be between 15% and 50%. As stated by the WHO, the best means of preventing Long COVID is to avoid infection.

Prevention, monitoring cases, increased funding, patient support (including financial), and establishing national and regional decision-making bodies that incorporate scientific research as well as the lived experience of patients, are among the cornerstones of a Long COVID action plan that is urgently needed. Long COVID can affect anyone. Acknowledgement and resolute action on this pervasive issue are long overdue.

list of signatories

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